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PRINCIPAL INVESTIGATOR: James C. Coyne, Ph.D.

CONTRACTING ORGANIZATION: University of Michigan

Ann Arbor, Michigan 48109-0708

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James C. Coyne, Ph.D.

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Predictive testing is now possible for altered genes which convey heightened risk of breast and ovarian cancer. Testing is already being offered to our sample of high-risk women who have been participating in genetic linkage and mutation studies and it is becoming more generally available. In the absence of prior research, we are faced with a need for basic descriptive data concerning women at high-risk for early onset breast cancer and their families; their psychosocial assets and liabilities, their attitudes and beliefs, their intention to seek predictive testing, and their preparedness for possible results. This project involves a prospective study of high risk women drawn from a hereditary cancer registry and their families in a time period spanning from prior to the offering of predictive testing to a year following their decision whether to obtain such testing. The second year of the project was marked by the continued progress of the study, including movement of some women into the follow up phase. Important results include findings concerning the nature of social support processes in these high risk families and the gathering of further evidence of the positive adjustment of these women. Comparative studies utilizing community samples are also being launched.

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INTRODUCTION

This project involves a prospective study of women who are at high risk for early onset breast cancer and their families in a time period spanning from prior to the offering of predictive testing to a year following their decision whether to obtain such testing. Predictive testing is now possible for mutations of both the BRCA1 and BRCA2 genes. Only about 5-10% of all breast cancer is believed to be hereditary in nature, but this figure could be as high as 20% for early onset breast cancer. Furthermore, it has been estimated that 15-45% of all families with multiple cases of breast cancer and as much as 80% of families with elevated rates of both early-onset breast and ovarian cancer carry mutations of either BRCA1 or BRCA2, although these figures may be somewhat lower in the general population than in the hereditary breast and ovarian cancer registries from which they were derived. It has also been estimated that female carriers have a 55-85% risk of developing breast cancer and a 20-40% risk of developing ovarian cancer before the age of 70. Male carriers of these altered genes are at somewhat increased risk for prostate and colon cancer, and male carriers of BRCA2 have a 6% risk of breast cancer. Cancer susceptibility conferred by BRCA1 and BRCA2 mutations is transmitted as an autosomal dominant trait which means that the mutations are inherited from either parent, and offspring have a 50% risk of inheriting the parental mutation. Options for women who test positive for an altered gene related to breast cancer include increased surveillance, prophylactic mastectomy and Oophorectomy, and for some, participation in a chemo-prevention trial. None of these measures have proven to be entirely efficacious and all have known limitations.

Testing has been offered to our research sample of high-risk women who have been participating in genetic linkage and mutation studies, and it has now also become available in the community. As many as 1 in 300 American women are carriers of mutations of these genes, and larger numbers can be expected to face the dilemma of whether to seek testing. Mutations of these genes are the first for which widespread genetic testing for risk of late onset disease is appropriate, and the availability of the test raises some daunting and largely unprecedented issues. Women with positive family histories of breast cancer have expressed considerable interest in obtaining predictive testing. Yet little is known about the extent to which women who indicate they intend to obtain testing actually follow through with it. Furthermore, little is known about the anticipated benefits and drawbacks of knowledge of risk status which influence their choice, or about the psychological and social costs to these women and their families of having access to such information. Positive findings carry the threat of psychological and psychiatric morbidity for the women and family members, the disruption of family relationships, and the impairment of the women's surveillance and adherence behavior, but the degree of vulnerability and factors which identify the individuals and families at greatest vulnerability have not yet been determined. Yet, negative findings or not obtaining information concerning risk status may also have detrimental effects on the women and their families.

In the absence of a large body of directly relevant prior research, we were faced with an urgent need for basic descriptive data concerning women at high-risk for early onset breast cancer and their families, including their psychosocial assets and liabilities, their attitudes and beliefs, their intention to seek predictive testing, and their preparedness for possible results. This information was needed immediately for in planning for testing becoming made available on such a large scale basis. Yet, we also recognized that we had a historical opportunity to utilize these data in a prospective study of stress, coping, and decision making processes in these women and their families. We had the advantage of initial data having been obtained just prior to predictive testing for BRCA1 and BRCA2 becoming an option for the individual women.

The project was designed as a longitudinal study of a sample of at least 300 high-risk women who are among the first being offered the option of testing for BRCA1 and BRCA2 and their family members. With expansion of the Hereditary Breast and Ovarian Cancer registry we have been increasing our sample to almost 500 women which is now our goal. Women participating in our study receive baseline in-depth assessment by questionnaire and telephone interview. Initial assessments had been started at the point of receipt of funding from the DoD. Funding from the DoD Breast Cancer Initiative was sought to complete initial assessments and to follow the women over time with 4 reassessments: When testing for BRCA1 becomes available to the individual women, within 8 weeks after receipt of any results, and 6 and 12 months after testing. Husbands of the high risk women are also assessed by questionnaire and they are being reassessed along with siblings of the women at 6 months following the women's receipt of results. Our sample is well described medically and in terms of family history. The women and their families are being assessed with a set of psychosocial measures which are carefully chosen for their likelihood of immediate relevance to planning and the design of clinical protocols, but also for their use in understanding of basic individual and family stress and coping processes. Variables assessed include attitudes and beliefs; personality traits; social support and family functioning; psychological distress and psychiatric morbidity; and decisions and behavior relevant to their management of risk for cancer. These measures will also allow estimation of psychosocial costs associated with the option of testing and modeling of the intention whether to obtain testing and subsequent decision-making The resulting longitudinal data will have a direct application in and behavior. estimating the need for services, refining appropriate clinical protocols, and suggesting requisite training for personnel providing services.

The first overall objective of this study has been to assess psychological distress, current and past psychiatric disorder and impairment in women at high-risk for breast and ovarian cancer who are anticipating the prospect of genetic testing. Establishing base rates of distress and impairment permits us to evaluate the mental health needs of these women anticipating testing, and it also serves as a first step in

evaluating the incremental distress associated with receipt of results. That is, levels of distress and morbidity following disclosure need to be evaluated in terms of what these levels were prior to disclosure. Without these data, it could not be determined if psychological distress and disorder following testing actually represent a reduction from pre-existing levels. The second objective has been to compare the two groups of women within our sample: One group who had been previously diagnosed with breast cancer, and one group who had not yet been affected. Initial differences between the two groups are important for the evaluation of the extent to which unaffected women subsequently become like affected women upon receipt of findings that they carry the altered gene. On the other hand, it might prove to be the case that heightened awareness of high risk status among unaffected women has already resulted in comparable levels of distress and disorder. A final objective has been to evaluate the extent to which our self-report data are successful in identifying current and past psychiatric diagnoses. Self-report screening instruments are economical and readily administered, but tend to have the disadvantage of low specificity as a means of identifying psychiatric cases (Coyne, 1994). Furthermore, the prevalence of both distress and disorder in a given population may affect the performance of the cutpoint which has been established for screening measures. Thus, one study found that the high rates of elevated scores on a screening instrument, but low levels of depression among adolescents rendered the established cutpoint for the screening instrument useless in detecting depression (Roberts, Lewinsohn, & Seeley, 1991) The inclusion of both self-report measures and diagnoses based on semi-structured interview allows us to examine the performance of the self-report measures in terms of their possible use as the first stage of two-stage strategies for identifying psychiatric morbidity. their specificity proved to be as modest as anticipated, low scores might still prove valuable in screening out women who would be unlikely to be found to have psychiatric morbidity in a diagnostic interview.

In the second year, we have also had the objective of addressing the issue of social support processes in the lives of high risk women. This objective will continue as the women progress through the opportunity to obtain results and the follow up periods. However, it was important to establish the role of social support in their initial adjustment. Furthermore, we were interested in the involvement of husbands in the women's decision making concerning cancer risk management and whether to testing. Spouses are usually the most important source of support for married persons (Brown & Harris, 1978; Coyne & DeLongis, 1986). Yet, the women in our study are members of high risk families, with first-degree female relatives in similar The support and information close female relatives provide, how these predicaments. relatives cope with their own dilemma, and the decisions about testing they make are likely to have profound effects on the high risk women. It may be that as a result of the mobilization of social support around the shared risk of cancer, female relatives come to have more influence on the distress levels of these women, and the spouses correspondingly less.

BODY

The project involves an in-depth assessment and tracking of four interrelated groups: (1) at least 300 proband women (presently 480) who have a risk for early onset breast cancer based on two or more family members being affected by cancer and who will be among the first persons to have access to testing for alterations of the BRCA1 and BRCA2 genes (2) the spouses of the approximately 400 women who are married: (3) a stratified random sampling of 120 of the women's unaffected sisters (those who have not been diagnosed with breast cancer) and (4) 80 brothers. variables include the women and family members' stress and social support processes, including cancer-related stress and support; psychological distress and psychiatric morbidity; marital and family functioning; psychological characteristics presumed to affect the women's information-processing, decision-making, and subsequent adjustment; the at-risk women's intentions to seek predictive testing and anticipated outcomes and plans for use of the information; relevant attitudes, beliefs, and expectations; and current surveillance and adherence behaviors. Initial assessment of the proband women is by self-report questionnaires and telephone interviews. Subsequent reassessments of the proband women's current cancer-related stress, support and beliefs, attitudes and intentions, distress, and psychiatric morbidity will also be by telephone interview and questionnaire. The assessment of husbands and siblings is by self-report questionnaires. The at-risk women, spouses and siblings are then reassessed as the option of predictive testing is made available to the individual women. A second reassessment of the individual women will occur after 8 weeks testing has occurred and results are available, or when results would have been available had the proband woman not declined testing Follow up assessments will occur at 6 and 12 months.

PROCEDURE AND ACCOMPLISHMENTS TO DATE

Summary

As reported in our first annual report, the initial year of the study was marked by the meeting of key objectives and successful confrontation with a variety of challenges and opportunities. Expansion of the Hereditary Breast and Ovarian Cancer Registry from which subjects are drawn allowed recruitment of a larger sample for baseline assessment. This was fortuitous because preliminary testing of blood samples from women already affected by breast and ovarian cancer in high risk families has now revealed that BRCA1 and BRCA2 account for less of the ostensibly hereditary breast cancer than previously predicted. At the present time, women from families that do not have an affected woman with a known BRCA1 or BRCA2 mutation are not generally offered testing. The implications of this are that many of the women in our

sample will not progress to the stage of actually confronting the testing dilemma. As noted below, there may also be an increased psychological burden on affected women seeking testing: Whether family members can be tested will depend on their results. Our substantially augmented sample allows us to nonetheless have a more than adequate size and statistical power for women who do progress to a choice about testing. The first year was also marked by delays in the offering of testing to individual women for a variety of technical and practical reasons spelled out below. We had anticipated this and had previously designed an interim assessment to be administered if one year passed after baseline assessment without a woman being offered testing. This interim assessment also served to reduce the burden of the baseline assessment by redistributing some of our trait measures to a second testing and it also involved the re-administration of measures of distress and other state variables likely to fluctuate over such a time period. As planned, women who progressed to the opportunity to get their results received these measures in their pre-counseling assessment. We also took advantage of a change in the of the Hereditary Breast and Ovarian Cancer Registry. Persons, both male and female, who have gotten results of genetic testing elsewhere are now being entered into the registry for the purposes of long term follow up. We have included them in our Long Term Follow up tracking sample. For some purposes they will be separated for data analysis, but for other purposes they can be combined. This addition will very likely make our sample the largest data base concerning persons who have received genetic testing for risk of breast cancer.

Our second year has been marked by sustained progress. We have continued data collection, refined our research objectives, and modified our instrumentation based on initial results. Our interim assessment continues to allow us to monitor state variables and obtain additional trait measures for women having more than a year elapse between initial assessments and actually being offered testing. We have also been responding proactively to a number of exigencies, including a lower uptake of genetic testing than anticipated and a greater proportion of noninformative results among women who obtain testing. We have been enrolling new women in the study as women get recruited to the larger Hereditary Breast and Ovarian Cancer Registry. This should continue through this next year. As anticipated, women who were already enrolled in our sample are continuing to receive the opportunity to obtain testing. Some have now progressed to 6 month follow up. Based on initial results, we are setting up data collection from samples of women in the community seeking genetic testing, and we have also been adapting instrumentation to women who receive uninformative results.

Women who had initially expressed interest in testing are responding at a lower rate than anticipated to the actual opportunity to obtain their individual results. Some of their declining of testing is passive, expressed by members of high risk families not responding to letters notifying them that their results are now available or by their

not returning consent forms. This is quite consistent with past experience with testing of persons at risk for Huntington's disease, but it remains an important phenomenon to study. Another investigator group has concluded that members of high risk families who decline testing in may suffer adverse psychological consequences (Lerman et al., 1997). However, we have shown that declining testing may represent a rational decision to defer testing when other stressors are present in women's lives (Coyne, Weber, & Sonis, in press). Furthermore, it appears that decliners remain at lower levels of distress than a comparison group of patients drawn from primary care waiting rooms. Nonetheless, we have designed and implemented systematic follow up of such decliners in order to minimize selection bias in our data. Furthermore, we will be using our initial data to explore predictors of discrepancies between initial intention to obtain testing and actually obtaining it.

There has been a higher proportion of women in our sample than anticipated who have been affected by breast or ovarian cancer, but who are not found to have a known mutation of BRCA1 or BRCA2. This is consistent with other evidence of the existence of additional genes associated with hereditary risk for cancer. poses some important psychosocial issues which we are exploring. Namely, affected women who receive uninformative results could experience distress because they are left in a highly ambiguous situation with respect to their own risk and that of family Their prior coping efforts may have been organized in the belief that testing would resolve a profound uncertainty in their lives, namely, whether being in a high risk family meant that they were personally at increased risk of cancer. many of these women will have expressly sought testing to aid family members in determining their individual risk. We are tracking these women and adapting our instrumentation to their predicament. This is likely to be a widespread issue with testing in community settings. We are in what amounts to a unique situation in investigating the effects of noninformative results. Other investigators are relying on hereditary registries in which a smaller number of large families have known mutations. As a result, they are unlikely to have as many members of high risk families receiving uninformative results.

Initial results revealed that women in our sample were socially advantaged in terms of education, income, and marital stability. This is consistent with what has occurred with genetic counseling and testing more generally, and Huntington's disease in particular. Yet, because of media attention, the prevalence of mutations of BRCA1 and BRCA2, and the promise of potentially modifying risk of cancer, interest in genetic testing may be higher in the general population than for other late onset conditions. It is therefore crucial to understand differences between registry samples and women from the general population expressing an interest in testing. Without appropriate comparisons, generalizing from samples derived from hereditary cancer registries may be unwise. We have taken two important steps to address this issue. First, we have sought use of CCOP samples in Michigan and Ohio by formally submitting a concept

letter to Dean Brenner, M.D. Upon approval, we will proceed with negotiation of data collection in these community settings. Secondly, we are in the process of negotiating data collection from clinics in the University of Pennsylvania Medical System. Availability of these comparison samples will substantially increase the utility of data we have been collecting from our registry sample.

Our initial findings have also been that women in our sample are remarkably free of psychological distress and psychiatric morbidity. Basically, we set out to study a population ostensibly at psychological risk and we are encountering one which apparently is quite resilient. To better understand these issues, we have refined our assessments of these women's appraisal of the opportunity to obtain testing. Our scaling technique for this is an important methodological innovation in itself. We also have taken advantage of our interim assessment of the women in our sample and the initial assessment of their husbands to explore the role of social support processes in the apparent resiliency of these women. One hypothesis is that explicit awareness of the high risk status of these families has led to the mobilization of support processes organized around this status. If this is so, women in the community seeking testing may not share this advantage. This should prove to be one of the many valuable points of comparison between our registry and community samples.

Methods

Women and their families participating in this study were drawn from the Hereditary Breast and Ovarian Cancer Registry originally started at the University of Michigan, but now housed at the University of Pennsylvania. There were two sets of criteria by which women could be included in the registry. Unaffected women had to have at least two cases of either breast or ovarian cancer in their family, and affected women had to have at least one other family member who had been affected. A periodic informational letter to women enrolled in the registry made reference to the possibility of an impending longitudinal study of them and family members. recruit subjects for the psychosocial component of the University of Michigan/ University of Pennsylvania study, a cover letter, consent form, and questionnaire were sent to eligible enrollees in the registry. After the baseline questionnaire and consent form were returned, subjects were contacted by telephone in order to answer any questions and schedule the telephone interview. If we received neither a questionnaire or a mail-back refusal form, we called subjects, explained the study, and offered to send another packet if necessary. At the point of actual receipt of funding, some of the women had already participated in the initial assessment and had been alerted to the possibility of their being asked to continue in a longitudinal study and to enlist family members. Women continuing to participate in the study are asked to solicit the involvement of spouses. Given the sensitive nature of risk information, concerns about confidentiality dictated that we utilize the women rather than contact the family members directly. We discussed the rationale with the women for their

family members' involvement, underscored the voluntary nature of their choice whether to facilitate their family members' participation in the study, and if they so chose, ask them to provide names and permission to contact these relatives.

Our initial sample is now variously at the point of receiving pretesting, immediate post-testing, or 6 month follow up assessments. Our recruitment and assessment of spouses and sisters proceeded on schedule. We are also adapting our schedule of assessment for women who are newly recruited into the hereditary cancer registry.

As noted in last year's report, our ability to track these women and their families through the course of their being offered testing was dependent upon them actually being given this opportunity. A number of factors affected the offering of testing in general and to specific individuals. Actual testing is now proceeding in our sample, but only after considerable delay and is almost entirely limited to affected individuals or a few other women in families with known mutations. Accurate mutation analysis remains challenging. Both BRCA1 and BRCA2 are very large genes and mutations are scattered throughout the genes. Analyses of either of the entire genes would be labor intensive and expensive. Available laboratory techniques do not detect mutations on non-coded regions of the genes, but these may account for as many as 5-10% of Therefore, at the present time, the accuracy and informativeness of testing is hinged upon whether there is a known mutation of BRCA1 or BRCA2 identified in an individual in the family affected with either breast or ovarian cancer. If such a known mutation exists, then the detection of that mutation in another member of that family is highly accurate and informative. If no such mutation has been identified in a particular family, then the only informative result for individual family members is when a specific mutation of BRCA1 or BRCA2 is identified. In the absence of mutation having been found in a family, a negative testing finding for a given individual is not informative. This does not mean that the cancer is not associated with a cancer susceptibility gene, only that no such mutation can be identified at this time. result of all of these considerations is that not every individual is appropriate for testing. For the University of Pennsylvania Hereditary Breast and Ovarian Cancer Registry, the decision was made to analyze first already collected blood samples from affected women. If an affected woman was found to have a mutation, testing is offered to her family. As in other hereditary breast cancer registries, it is being found that many ostensibly high risk families do not carry a known mutation of BRCA1 or BRCA2. This is stimulating a search for other genes associated with risk of breast cancer, but it also means that for now many women in the sample will not receive Some have already been sent a letter explaining the predicament of their families with respect to testing. These women will continue to be studied. Essentially they had met criteria for inclusion in the registry, and based on this, they were led to believe that genetic testing would be an option. They are not being told that they are not members of a hereditary breast and ovarian cancer family, only that the families are not characterized by a known mutation of BRCA1 or BRCA2. This outcome is

worthy of investigation and may have attendant psychological distress and other untoward consequences associated with it. Fortunately, we have baseline assessments of these women and as noted above, we have instituted follow up assessments of them.

Women in the Hereditary Breast and Ovarian Cancer Registry are scattered across the country. In order to receive results, women who are not in close proximity to the University of Pennsylvania, University of Michigan, or other select sites must identify a physician and through that physician, provide a clinical consent. Only then will results be released. The shortage of such physicians and some difficulties in their understanding of the consent process led to some delays, but release of test results is now proceeding. Concerted efforts are being made nationally to increase the availability of individuals qualified for counseling, disclosure of results, and follow up. We continue to coordinate our assessments with information from the University of Pennsylvania and collect data as women proceed through the process of being given the opportunity to obtain test results.

Measures

Our selection of measures meets or exceeds what was proposed in our original grant application. Copies of our batteries of instruments are included as an appendix and this year's report contains recent additions tailored to the progression of the study. Tables 1 (next page) lists the major measures.

Table 1: Initial Data Collection

Proband Women

	Troound Women	
Questionnaire	Interview	Interim Assessment
Demographics	Contextual Rating of	HSCL-25, MOS-36
Health Locus of Control	Cancer Threat:	Cancer Worries
Risk Perception	Affected Relatives	FAD, Short-Form DAS
Intention to Seek Testing	Relationship to	Quality of Social Support
Knowledge, Beliefs and	Proband	Life Cycle Issues
Attitudes	Outcome	Receipt of Individual,
Reasons for Seeking Testing	Involvement of	Group, & Family,
Anticipated Reactions	Proband In Care	Counseling & Education
Cancer Worries	Effects on Proband's	COPE
Stressful Life Events	Life	Relationship-Focused
Optimism (LOT)	SCID Depression, Anxiety,	Coping
Miller Behavioral Styles	& Substance Use Modules	CBCL
Scale (MBSS)	Cancer-Specific Support	Evaluation of Preventive
Hopkins-25, MOS-36, AUDIT	Processes	Options
Present and Future Self-		
Concept		
Dyadic Adjustment (DAS)		
General Family		
Functioning (FAD)		
Social Support & Cancer-		
Related Support Processes		

Husbands Questionnaire

Demographics	COPE	Stressful Life Events
Health Locus of	Knowledge, Beliefs	CBCL
Control Risk	and Attitudes	LOT, MBSS, Hopkins-
Perception	Anticipated Reactions	25, MOS-36
Worries About Wife's	Social Support &	AUDIT
Risk of Cancer	Cancer-Related	DAS, FAD
Preference for Wife's	Support Processes	
Testing		
Relationship-Focused		
Coping		

<u>Sample</u>

Our sample currently consists of 480 women who have completed baseline assessments. Of these, 472 completed the telephone interviews. To date, 363 interim assessments have been collected. Data from husbands are collected at the point of the women's interim assessment, and at this time, data have been collected from 224 husbands. Pre-Results data have been collected from 57 Probands and 58 siblings (25 brothers and 33 sisters). As of this report, 19 women have had their first post-results assessment and 11 have progressed to their 6 month follow up. We expect the rate of receipt of test results to increase markedly over the next few months. In addition, follow up data have been collected from 15 men and women in the long term follow up subsample. Table 2 presents an update of basic demographic data on the proband women. As can be seen, they are similar to other samples of persons seeking genetic services in that they are relatively well educated and high income.

Table 2

Demographic Characteristics by Breast Cancer and Marital Status.

	Affected		<u>Unaff</u>	ected
	Married (N=182)	Not Married (N=32)	Married (N=212)	Not Married (N=47)
Age	50.09 (10.56)	60.32 (12.41)	45.27 (10.70)	49.99 (16.38)***
Percent white	98.9%	96.9%	97.6%	97.9%
Percent Christian	68.3%	83.9%	80.2%	76.6%*
Percent completed some college	81.9%	67.7%	81.6%	83.0%
Percent employed outside home	62.6%	53.3%	65.4%	61.7%
Household income	\$53,600	\$25,000	\$53,900	\$33,900*
Percent first marriage	81.7%	NA	81.3%	NA
Percent ovarian cancer	3.4%	10.0%	NA	NA
diagnosis				
Years since breast cancer	7.55	12.54	NA	NA
diagnosis	(5.79)	(8.79)		
Percent in remission	89.9%	92.6%	NA	NA

^{*} p < .05, ** p < .01, *** p < .001

Interest in Obtaining Testing

Table 3 presents data concerning the intention to receive testing when it is offered. As can be seen, the majority of women express interest in obtaining results, but it remains to be seen the extent to which this expression of interest is reflected in the women actually choosing to receive their results when the opportunity is presented to them. Given the low rate of uptake of testing, an objective for our third year will be to model the discrepancy between intention and actually receiving test results using our full battery of psychosocial predictors.

Table 3

Intention To Receive Test Results

	ALL WOMEN	UNAFFECTED <u>WOMEN</u>	AFFECTED <u>WOMEN</u>
Definitely Will Immediately	64.2	55.2	75.0***
Definitely, Not Sure Immediately	10.2	15.5	4.2
Probably Will Immediately	9.4	9.7	9.2
Probably Will Not Immediately	4.1	9.0	4.2
Undecided	7.2	9.0	5.0
Probably Will Not	1.9	1.4	2.5
Definitely Will Not	0.4	0.7	0

***p<.001

Table 4 provides data concerning the women's reasons for obtaining test results. While their motivation to reduce uncertainty was expected, it is noteworthy that the next strongest reason for the full sample is to find out about their children. This result is consistent with our anticipation of the salience of such family issues in the reasons for getting testing. Moreover, now that it has been decided that testing is appropriate for unaffected women only when they are members of families with known mutations, the saliency of family issues for affected women is likely to increase.

Table 4

Reasons For Seeking Testing

	ALL WOMEN	UNAFFECTED WOMEN	AFFECTED WOMEN
To Plan for Future	46.4	62.7	30.7***
To Reduce Uncertainty	64.6	79.4	48.2***
To Be More Careful About BSE	34.6	46.0	21.9
To Decide About Prophylactic Surgery	47.1	55.6	32.5***
To Decide About Family Planning	5.8	11.9	2.6
To Assess Risk To Children	61.7	51.6	72.8**
Family Urges Testing	17.4	15.1	13.2
	*p<.05	**p<.01	***p<.001

Table 5 provides data concerning these women's perceived risk of breast cancer. These women's estimates of their risk is not inconsistent with being a female member of a high risk family.

Table 5

Perceived Likelihood Of Breast Cancer

	ALL WOMEN	UNAFFECTED <u>WOMEN</u>	AFFECTED <u>WOMEN</u>	
In the Near Future	35.2%	44.	7%***	22.3%
In Lifetime	47.8%	60.	3%***	31.9%

Baseline Distress and Psychiatric Morbidity

As we noted, one of our objectives for the first year was to analyze baseline data concerning psychological distress and psychiatric morbidity. The Hopkins Symptom Checklist served as the measure of distress and a telephone interview using modules of the SCID served as the measure of current and lifetime psychiatric morbidity. These data were analyzed in conjunction with baseline data concerning intention to get test results and cancer worries. In the second year, we have modified our earlier results based on continued accrual of subjects, although the pattern of remarkably low distress and psychiatric morbidity remains. Additionally, we completed sophisticated analyses of the performance of screening instruments. As dictated by the low preference of psychiatric disorder, the positive predictive value of positive screening for distress is quite low. Practically speaking, screening for psychiatric morbidity is not needed or efficient.

Cancer worries. This measure was administered to the unaffected group only. The women were asked how often they worry about developing breast cancer and also the extent to which their worries interfered with their everyday lives. These items had been validated in studies conducted by Caryn Lerman and her colleagues e.g. Lerman et al. 1994; Lerman & Croyle, in press; Struewing et al., in press).

Psychological Distress. The 25 item version of the Hopkins Symptom Checklist (HSCL-25) was used to assess psychological distress. Heshbacher, Downing, and Stephansky (1978) found this version of the questionnaire reliable and highly correlated with the standard 58-item version (Derogatis et al., 1974). The HSCL-25 has a better balance of sensitivity and specificity than a number of other screening instruments such as the CES-D (Heshbacher et al. 1978; Hough et al. 1982). There is extensive data using this scale with healthy, physically ill, and psychiatric samples (Cohen, Coyne, & Duvall, 1993; Coyne & Smith, 1991; Coyne & Sonnega, 1995, Pepper & Coyne, 1996).

Current Depression, Anxiety, and Alcohol Use Disorders and History of Depression. Like other self-report screening instruments, our measures of psychological distress and alcohol use have good sensitivity, but poorer specificity and they do not provide for diagnoses. A 2-stage screening in strategy is therefore appropriate (Dohrenwend & Shrout 1981; Newman, Shrout, Bland 1990). Women with elevated scores on measures of psychological distress and alcohol use and a subsample of those scoring below the cut points will be administered corresponding alcohol use and/or depression and anxiety sections of the Structured Clinical Interview for DSM-IV (SCID-IP; First et al 1994).

The SCID utilizes trained mental health professionals and yields DSM-IV diagnoses. addition to diagnoses, the SCID includes assessment of the severity of major depression according to DSM-IV criteria and assessment of past history of depression. The DIS utilizes lay interviewers, and one key difference between the two instruments is that the SCID utilizes the clinical judgment of the interviewer for decisions about explaining or rephrasing questions and accepting or probing respondents' answers. In contrast, the DIS is more like an interviewer-administered questionnaire with considerable constraint on what the interviewer can ask or infer (Coyne, 1994). Although the DIS has been used in the large scale ECA Study (Regier, Myers & Kramer 1984), there is some evidence of substantial discrepancy between the diagnoses made by lay interviewers using the DIS and standardized diagnoses made by psychiatrists (Anthony et al 1985). Moreover, discordance may be more frequent with nonpsychiatric populations when the depression being diagnosed is mild so that criteria are barely met by alternative rules, and this proves particularly important when correlates are examined rather than simple rates of detection (for a fuller comparison of the SCID-IP and DIS, see Coyne 1994). Discordance is similarly likely to arise when judgments must be made whether to consider heightened distress as an adjustment reaction, and such decisions are likely to be routine in assessing the proband women.

The SCID-IP is designed for use in a modular fashion so that an investigator can select, for a particular study, only those diagnostic modules that are relevant for a particular patient sample. For our purposes, the SCID-IP is modualized to assess history of depression and current mood disorders, alcohol use disorders, panic disorders, and

generalized anxiety, and adjustment disorders. This decision is based on our own experience assessing psychiatric disorder in primary care, but also the NYSPI experience assessing homosexual men seeking testing for HIV antibody (Williams et al 1991). They initially included psychotic screening questions, the other anxiety disorders, and somatoform disorders but these areas of psychopathology were virtually never detected, so they dropped these sections to decrease interviewing time.

Questions can be raised about the conduct of diagnostic interviews by telephone. However, previous studies have shown the concordance of phone-administered diagnostic interviews with face-to-face interviews (Kendall et al 1992; Wells et al 1988; Potts et al 1990; Baer et al 1993), and as with other major research centers, we have been having satisfactory experiences with telephone interviewing.

Table 6 presents the data derived from standard measures of breast cancer worries. Understandably, the women have a moderate degree of such worries, but what is noteworthy is that the follow up question concerning impairment indicates that such worries do not substantially interfere with their lives.

Table 6

Breast Cancer Worries Among Unaffected High Risk Women

How often do you worry about developing breast cancer (1= Not at All, 5= All the Time)?	2.87	
To what extent do any worries about breast cancer interfere with your life (1= Not at All, 5= All the Time)?	1.63	

Table 7 presents some new analyses of the MOS SF-36 data for the unaffected and affected women. As can be seen, the women did not differ for any of the SF-36 scales. Moreover, they exceed normative data for all scales. These data offer further corroboration of our previous findings that our combined sample is an exceptionally well adapted group of women.

<u>Mean Scores Of Physical And Mental Health Functioning For Women Affected And Unaffected By Cancer</u>

<u>UNAFFECTED</u>	AFFECTED		
WOMEN	WOMEN	<u>L</u>	
87.89	84.90	1.57	
86.20	85.74	.24	
83.02	82.18	.28	
80.89	76.36	1.37	
74.61	74.39	.16	
72.72	69.67	1.62	
72.43	73.98	68	
59.96	59.27	.35	
	WOMEN 87.89 86.20 83.02 80.89 74.61 72.72 72.43	WOMEN WOMEN 87.89 84.90 86.20 85.74 83.02 82.18 80.89 76.36 74.61 74.39 72.72 69.67 72.43 73.98	WOMEN t 87.89 84.90 1.57 86.20 85.74 .24 83.02 82.18 .28 80.89 76.36 1.37 74.61 74.39 .16 72.72 69.67 1.62 72.43 73.98 68

^{*}p<.05, **p<.01, ***p<.001

Note: Scores range from 0-100 with higher scores indicating a better health state.

Table 8(next page) presents the results obtained with the Hopkins Symptom Checklist. These results have changed only slightly with the accrual of more women. Interpretation of these results is assisted by making a comparison with our HSCL-25 data obtained with other samples, presented in Table 9(next page). Our sample, both affected and unaffected, is remarkably free of distress. This disconfirms expectations that at risk women seeking testing are a highly distressed group.

TABLE 8
Psychological Distress

	All Women	Affected <u>Women</u>	Unaffected <u>Women</u>
Hopkins-25	37.5 (9.2)	37.8 (9.2)	37.3 (9.0)
% in Clinical Range (Greater Than43)	23%	22%	24%

Table 9
Psychological Distress In Other Samples

Cohen, Coyne, Duvall (1993):	
Adoptive Nonclinical	
Mothers	34.52 (7.09)
Biological Nonclinical	
Mothers	36.25 (8.9)
Adoptive Clinical	
Mothers	43.64 (12.3)
Biological Clinical	44.00 (40.4)
Mothers	41.30 (12.1)
Coyne & Smith (1991)	
Wives of Post-MI	
Patients	41.8 (10.2) 32%
Coyne & Sonnega (1995)	
Wives of CHF Patients	47.1 (12.8) 49%
Female CHF Patients	46.6 (14.1) 62%
Pepper & Coyne (1996)	
Depressed Female	(5.0. (11.00)
Outpatients	65.0 (11.30)

Table 10 presents the updated results obtained in the assessment of psychiatric morbidity using the telephone-administered SCID modules. Consistent with the data concerning psychological distress, this is a remarkably intact group of women. given their high risk status. The lifetime rates of depression are well within normal limits, but their rates of current disorder are even lower than what is found in representative samples of community residing women. Thus, the anticipation by some that these women would have a high prevalence of depression and anxiety disorders was clearly not confirmed.

TABLE 10

Psychiatric Morbidity

	All Women	Affected Women	Unaffected Women
Current Major Depression	5 (1%)	4 (2%)	1 (.4%)
Lifetime Major Depression	87 (18%)	46 (21%)	41 (16%)
Current Major Depression (GMC)	2 (.4%)	2 (.4%)	0
Lifetime Major Depression (GMC)	10 (2%)	7 (3%)	3 (1%)
Generalized Anxiety Disorder	3 (.6%)	1 (.5%)	2 (.8%)
Mixed Anxiety Depression	3 (.6%)	0	3 (1%)
Dysthymia	2 (.4%)	1 (.5%)	1 (.4%)
Alcohol Use Current	1 (.2%)	0	1 (.4%)

Performance of Screening Instruments

Table11(next page) presents results of our analysis of the performance of the HSCL-25 as a screening instrument. As we noted, the performance of these instruments in detecting disorder in this study was constrained by the low prevalence (Elwood,1993). A score meeting or exceeding the clinical cut-point of 44 on the HSCL-25 yielded a sensitivity of 80%, a specificity of 80%, and a positive predictive value of 4% for depression. The respective values for the HSCL-25 with generalized anxiety as the criterion were 100%, 79%, and 3%. The respective values for the HSCL-25 with either depression or generalized anxiety as the criterion were 88%, 93%, and 7%. We also examined the performance of some simple screening questions tapping two weeks mood disturbance and impairment in functioning due to mood. Women's self-report on a 2-weeks mood disturbance screening question yielded a sensitivity of 60%, a specificity of 86%, and a positive predictive value of 5% for major depression. Little difference was found for including the requirement of a report of impairment for the 2-weeks mood disturbance in the form of seeking treatment or experiencing difficulties in interpersonal functioning.

Thus, we found that a low score on a standardized measure of distress was a good indicator that the women were not suffering from major depression or from an anxiety disorder. Yet persons scoring above a standard cut-point were unlikely to meet criteria for a clinical disorder, indicating that the measure had low positive predictive value. All self-report measures designed to screen for depression and anxiety are plagued by poor performance in general medical populations. However, the positive predictive value of 4% for major depression in the present study is still a fraction of the 15-30% obtained in primary care populations (Fechner-Bates et al. 1994; Hough et al. 1982). Indeed, a woman screening positive for depression on the self-report measure in the present sample would still only be as likely to be depressed as a randomly selected, unscreened woman in the general medical population (Coyne et al. 1994, Katon & Schulberg, 1992). What these results demonstrate is that as a group, the women do not require extensive psychological screening and diagnostic assessment. The use of screening instruments would be inefficient in that the vast majority of women who were distressed would not meet criteria for a clinical disorder.

TABLE 11
Performance of HSCL-25 as a Screening Measure

	<u>Sensitivity</u>	Specificity	Positive <u>Predictive Value</u>
Elevated HSCL-25 and Depression	.80	.8	.04
Elevated HSCL-25 and GAD	1.0	.81	.03
Elevated HSCL-25 and Either	.88	.8	.07

Social Support Processes

Table 12 presents results concerning the role of husbands and sisters in decision making about risk of breast cancer. It is clear across items that husbands have more of a role in decision making than sisters do, and that the women are at least as satisfied with their participation as with their sisters' participation. Thus, evidence does not favor the notion that the shared high risk status of these women would shift such social support processes toward a greater emphasis on the female relatives and a decreased emphasis on the spouse.

Table 12
Social Support Processes

<u>Likert-Scale Items</u>	Spouse M (SD)	Sister M (SD)
Discuss breast cancer with him/her	2.84 (.92)	2.64 (.93)**
Satisfaction with these discussions	3.23 (.86)	3.20 (.91)
Discuss BRCA1 with him/her	3.02 (1.03)	2.67 (1.16)***
Importance of his/her opinion in your getting BRCA1 testing	2.93 (1.14)	2.37 (1.25)***
Importance of his/her opinion in making decisions about reducing risk * p < .05, ** p < .01, *** p < .001	3.11 (1.12)	2.49 (1.19)***

Table 13 presents bivariate relationships among psychological distress, breast cancer worries, and social support. As can be seen, social support is a key determinant of levels of distress. In particular, for married unaffected women the simple bivariate relationship between marital satisfaction and distress is as great as the effect of breast cancer worries.

Table 13

<u>Bivariate Pearson Correlations Of Distress, Marital Adjustment, And Support Variables For Married Women¹</u>

	1	2	3	4	5	6	7
1. Hopkins	1.00	NA	44***	22**	.30***	22**	.14
2. Breast Cancer Worry	.30***	1.00	NA	NA	NA	NA	NA
3. DAS	35***	11	1.00	.50***	44***	.19*	10
4. Spouse Support	08	04	.52***	1.00	51***	.36***	14
5. Spouse Unsupportive	.25***	.04	51***	53***	1.00	.00	.21*
6. Sister Support	16*	10	.03	.21**	06	1.00	35***
7. Sister Unsupportive	.13	.11	09	02	.21**	54***	1.00

^{*} p < .05, ** p < .01, *** p < .001

¹Affected women are above the diagonal and unaffected women are below.

Table 14 presents results of regression analyses shedding more light on the relative importance of social support processes and breast cancer worries. As can be seen, social support plays more of a role in the distress levels of these women than does breast cancer worries. Negative involvement from spouses and positive involvement from sisters matter most.

Table 14

Hierarchical Regression Examining Relation of Positive and Negative Support to Psychological Distress with Controls for Demographics and Breast Cancer Worries.

Predictor Variables	Change in R2	В
Step 1: Demographic Variables	.03	
Age Breast Cancer Status Time since Diagnosis ^a		.003 .22** 20*
Step 2: Breast Cancer Worries ^b	.04**	.45**
Step 3: Spouse Support	.08***	
Positive Behaviors Negative Behaviors		.05 .30***
Step 4: Female Family Member Support	.03*	•
Positive Behaviors Negative Behaviors		18** 02
Full Predictor Set	R2 = .17***	

^a Only entered for affected women. ^b Only entered for unaffected women; affected women were not asked this question.

^{*} p < .05; ** p < .01; *** p < .001.

DISCUSSION

At their baseline assessment prior to being offered genetic testing, both women affected and vet unaffected by breast cancer were remarkably free women in our sample were remarkably free of psychological distress and psychiatric morbidity. Despite their increased risk for breast and ovarian cancer as well as their repeated exposure to breast cancer either in themselves or their relatives, they compared well with women drawn from other samples. Our findings have a number of implications. Most importantly, it appears that when the women approach the process of counseling, education, and decision making about testing, they will not be impaired by their preexisting psychological state. That is not to say that the actual experience of counseling, having to make a decision about testing, or the receipt of positive results will not engender distress. However, the assumption that these women will approach the process of genetic testing with distress and psychiatric morbidity was not substantiated by our findings. Rather, the results suggest that any substantial elevations of distress and psychiatric morbidity following the counseling process are best attributed to that process and not to the preexisting state of the women. It follows that efforts to manage psychological distress and the education and consent process should focus on acute needs, rather than be based on the assumption of chronic psychological problems.

The findings reported in this study have a number of implications that go beyond the question of determining the psychological state of women seeking predictive testing for risk of breast cancer. We have demonstrated that long-term survivors of cancer can be relatively free of psychological distress and psychiatric morbidity. Even though over half our sample were survivors of breast cancer and had a greater lifetime incidence of depression than the unaffected women, these women were well within the expected prevalence for a representative sample of community residing women. The low levels of distress and morbidity reported in this study suggest that previous findings of elevated distress may be confined to early adjustment to a diagnosis of cancer, or to the advanced stages of the disease. Our findings add to accumulating evidence than cancer does not necessarily result in psychiatric morbidity. Moreover, the discrepancy between the levels of distress in our sample and the levels of psychiatric morbidity further heightens the importance of not inferring psychiatric disorder from elevated distress.

We set out to examine the psychological vulnerability of women anticipating genetic testing. What we have ended up demonstrating is the resilience of these women. We believe that attention can be profitably turned to better understanding why these women defy the not unreasonable assumption that they are a distressed, depressed, and anxious group. The experience of living with familial risk of cancer may well have had a resiliency-building effect that more than cancels any vulnerability associated with it. The particular aspects of this experience that cultivate resiliency and

vulnerability need to be specified. As others have noted, adversity can produce resiliency as well as vulnerability, and women anticipating testing provide an excellent opportunity to study this (e.g., Schaeffer & Moos, 1992).

The suggestion from the Huntington disease studies is that persons who are at risk, and who have received positive results do not experience long-term negative psychological consequences. Despite these findings, there has been some tendency to dismiss this as denial. Our data do not support this idea. Our findings of a lack of morbidity were based on validated measures of self-reported distress and carefully We are concerned about pathologizing what appears to constructed clinical interviews. The claim that this only represents psychological defensiveness be good adjustment. or maladjustment needs to be substantiated with measures of these presumed processes and not simply established on the basis that these people are low on disorder and morbidity. We favor a more charitable explanation of the low levels of distress and impairment in high risk women. We propose that for both affected and unaffected women, genetic testing is ostensibly an acute stressor, but it has the prospect of resolving a longer term stress process by reducing uncertainty. who come from families where there is a high incidence of breast or ovarian cancer are likely to have preconceptions of their risk for breast cancer as well as of their options for dealing with it. Though we might presuppose that the anticipation of testing may be stressful, for some women it is an opportunity to confirm what they believe they already know and to organize their lives accordingly. For others there is the hope that contrary to their existing perception of risk for cancer, they will be found not to have the gene.

In our second year, these results have been sustained with continued accrual of women in our sample and we have had additional findings related to the performance of screening instruments and the role of social support processes in the lives of these women. Our results do not suggest the utility of routine screening of these women for psychiatric morbidity. As seen in low positive predictive values, the exceptionally poor performance of screening instruments is dictated by the low prevalence of psychiatric disorder.

It should be pointed out that ours is the only study of women from hereditary breast cancer registries which incorporates interview-based ascertainment of psychiatric diagnosis. Other studies rely exclusively on self-report. Our results suggest that not only are these women low in distress but, as seen in our analysis of the performance of measures of distress, these self-report measures are poor indicators of psychiatric disorder. This suggests that other investigators should be careful not to over interpret the clinical significance of distress in their sample. Indeed, what distress is to be found may represent adaptive worrying, rather than maladjustment.

Our findings concerning social support processes were not entirely anticipated. The women are satisfied with the support they receive and this support contributes to their adjustment. However, despite their shared risk status, female relatives are less involved than husbands in decision-making. The practical implications of this finding are that it is important to include husbands in counseling and education because it is crucial that they be adequately informed and prepared for the role they play in their wives' decisions. Finally, our multivariate analyses put breast cancer worries of these women in a larger perspective. Despite their high risk status, social support processes remain a key determinant of their adjustment. Such processes may be important to their overall positive adjustment. It remains to be seen if women in the community seeking testing similarly have the benefits of such support.

We remain concerned about the generalizability of our findings and those of other investigations of high risk women drawn form registry samples. Members of high risk families jointly participate in these registries, and they typically have marshaled considerable social support to manage their shared sense of being at high risk for cancer. Participation in these registries has also given these women exceptional opportunities to become informed about their risk of cancer and genetic testing, to come to terms with their risk status, and to evaluate the advantages and disadvantages of testing for themselves and their families.

In contrast, women from the community seeking testing are likely to be less socially advantaged and less informed or psychologically prepared for the dilemma of whether to proceed with testing. For these women, the decision to pursue testing may be precipitous and tied to recent stressors such as a positive mammography or the diagnosis or death of a family member. Pre-existing psychological distress may impair these women's efforts to become educated and to decide on the merits of testing for them. They may be naive about the issues of insurance and social discrimination associated with being known to have an altered gene. Social support related to being at high risk and to deciding about testing may be deficient or absent. Without appropriate services there is the prospect of these women may obtain testing without being adequately informed consent and they may negative psychosocial consequences without achieving the intended benefits of testing. Yet, at the present time, we lack the knowledge base needed to specify just what are appropriate services. Results from our community studies will address this need for a better understanding of women in the general population seeking testing. The intent of this work is to generate data having direct and immediate application in the refining and evaluating of urgently needed clinical protocols..

CONCLUSION

As noted in last year's report, our project made substantial progress in the first year in its implementation, confronting of a variety of methodological and logistical challenges, and its timely production of empirical results concerning the baseline adjustment of these high risk women anticipating the opportunity to receive genetic testing for risk of breast and ovarian cancer. The excellent mental health of these women shifted the focus of our research from efforts to predict baseline vulnerability to efforts to understand their resiliency in the face of their risk for breast cancer. As a byproduct of this effort, we produced data from our affected women which are optimistic concerning the mental health of longer term cancer survivors.

In our second year, we have produced results arguing against the utility of routine screening of these women for psychiatric morbidity. Furthermore, we showed that other investigators who do not have the benefit of interview-based assessment of psychiatric disorder should be cautious in interpreting distress among high risk women as psychopathology. We have also shown the relative importance of social support processes in the lives of these women, and in particular the role of the spouse for married women.

Looking forward to our third year, we will have the benefit of data resulting from the progression of these women through the opportunity to obtain testing and into the follow up phase of the study. Furthermore, we will have important comparison data from community samples.

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APPENDICES

Included with this report are copies of all of the questionnaires used to date:

Proband Post-Results Questionnaire-2 (6 Months)

Women's Health Study Questionnaire (Baseline Questionnaire Affected and Unaffected versions)
Telephone Questionnaire
SCID Questionnaire
Interim Questionnaires (Affected and Unaffected Versions)
Spouse/Partner Questionnaires (Affected and Unaffected Versions)
Proband Pre-Results Questionnaires (Affected and Unaffected Versions)
Siblings Pre-Results Questionnaires (Brother and Sister Versions)
Proband Post-Results Questionnaire-1 (4-8 weeks)





WOMEN'S HEALTH STUDY QUESTIONNAIRE

Phone Number	
Best time to reach yo Weekdays Weekday evenings Weekend days Weekend evenings Anytime	u:
Other:	
s there an alternative	e phone number where we may reach you

Today's Date	
Today's Date	

Back	ground	Data

A1.	Date of Birth	Month	Day	Year	
A2.	Ethnic Background:	White Hispanic Native American		Black Asian Other	
A3.	Religion:	Catholic Jewish None		Protestant Other	
A4.	Are you currently (please	check one)?	☐ M ☐ N m ☐ Se ☐ D:	ngle farried ot married, but arriage-like rela eparated ivorced Tidowed	living in a steady, tionship
A5a.	If you are currently married Month Ye		te of your	current marriag	ge?
A5b.	Is this your first marriage?	Yes	No 🗆		
A6.	How many children do you	have?	_		
	A6a. Number of children	living at home			
	A6b. Number who are un	ider age 6		_	
A7.	Are you currently working	for pay outside the	home?		
	Yes □ No				
A8.	If yes, about how many ho	ours per week are y	ou worki	ng for pay?	
	Less than 10 10-2	0 21-30)	31-40	41 or more

A9.	What is the highest level of education you have completed? (Check one)
	 □ Less than 9th grade □ Dropped out of high school □ Completed high school □ Some college □ Completed college □ Some graduate or professional training □ Completed graduate or professional training
The Pleas	following two questions are optional , but we hope that you will provide this information to check the appropriate box.
A10.	What is your household's total income? (Check one) ☐ Less than \$10,000 ☐ \$10,000 to \$19,999 ☐ \$20,000 to \$29,999 ☐ \$30,000 to \$39,999 ☐ \$40,000 to \$49,999 ☐ \$50,000 to \$59,999 ☐ \$60,000 to \$69,999 ☐ Greater than \$69,999
A11.	How many people (adults and children) does this income support?
	SECTION B
B 1. 1	Have you ever been diagnosed with breast cancer? Yes □ No □
B2. 1	Have you ever been diagnosed with ovarian cancer? Yes \square No \square
B3. I	Have you ever had any of the following surgical procedures? (Please check all that apply).
	Lumpectomy (Removal of lump Oophorectomy (Removal of ovaries) from breast)
	Unilateral mastectomy (Removal Hysterectomy (Removal of uterus) of one breast)
	Bilateral mastectomy (Removal of both breasts)
B4.	Compared to the <u>average woman</u> , how likely are you to develop breast cancer? Much Less Likely Likely 1 2 3 4 5

B5.	Compared to other women in your family, how likely are you to develop breast cancer?						h Less cely		Much More Likely			
	now	iikciy a	ic you t	o deven	op orea.	ot carroo		1		2 3	3 4	5
B6.	Over futu		at do yo	u believ	e your	risk to b	e of dev	veloping	breast	cancer <u>i</u>	n the n	<u>ear</u>
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
B7.			at do yo <u>etime</u> ?		e your	risk to b	e of dev	eloping	breast	cancer <u>a</u>	nt some	<u>point</u>
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	
B 8.	risk t	for deve ur inter	cloping ation co	a form on the contract of the	of breas g this te	t and over	varian ca e presen	incer that t time?	at runs (Plea s	in famili se check	one re	heir wing this, what sponse).
								-		mes ava	ilable.	
				•						ediately.		
		I	will pro	<u>obably</u> t	ake the	test imn	nediatel	y when	it beco	mes avai	lable.	
		I	will pro	obably t	ake the	test, but	t not imi	nediate!	ly.			
		I	am und	lecided v	whether	I will t	ake the	test.				
		I	will pro	obably n	ot take	the test						
		I	will def	finitely 1	<u>not</u> take	the test	t.					
B 9.	If yo (Plea	u think ase che	you wil	l probab that a	oly or do	efinitely	take the	e test, w	hat are	your re	asons for	doing so?
		_ Т	o plan	for the f	uture.							
	To reduce the uncertainty.											
		_ Т	o know	I have	to be m	ore care	ful abou	it doing	breast	self exa	ninations	and getting
		re	egular c	heckup	s.							
		_ T	o make	decisio	ns abou	it wheth	er to ge	t preven	tive su	rgery.		
		_ T	o make	decisio	ns abou	t family	/ plannii	ng.				
				out the ri					ny chil	dren.		
				nembers		_			-			
			•	escribe)								

B10.	If you do a doing so?	not think you will probably or definitely take the test, what are your reasons for not (Please check all that apply).
		I am happier not knowing.
		It would be too upsetting to learn that I am at high risk for breast cancer.
		I believe I already know what my risk for breast cancer is.
		There would not be much I could do if I found out I was at high risk for breast cancer.
		I do not feel able emotionally to deal with testing.
		Family members do not want me to get testing.
		Risk to my insurance coverage.

B11. If you were to take the test and find out that you were not at high risk for breast cancer, what would you expect your reactions to be?

		Strong Disagr				rongly Agree
a.	I would feel wonderful.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would feel relieved.	1	2	3	4	5
d.	I would not believe the results.	1	2	3	4	5
e.	I would fall apart emotionally.	1	2	3	4	5
f.	I would feel guilty.	1	2	3	4	5
g.	I would still feel anxious.	1	2	3	4	5
h.	I would feel angry.	1	2	3	4	5
i.	I would feel prepared for the future.	1	2	3	4	5
j.	I would feel I had done all I needed to do.	1	2	3	4	5

B12. If you were to take the test and find out that you were at high risk for breast cancer, what would you expect your reactions to be?

		Strong Disagr	ly ee			rongly Agree
a.	I would feel relieved about being more certain.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would not believe the results.	1	2	3	4	5

		Strong Disage	gly ree		Si 2	rongly Agree
d.	I would feel guilty.	1	2	3	4	5
e.	I would be depressed.	1	2	3	4	5
f.	I would feel worried about the future.	1	2	3	4	5
g	I would just fall apart emotionally.	1	2	3	4	5
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5

B13. To what extent do you agree with the following statements?

	b13. To what extent do you agree with the following	Strong Disag	gly			trongly Agree
a.	Mammography is effective in the early detection of breast cancer.	1	2	3	4	5
b.	Breast cancer that is detected early is curable.	1	2	3	4	5
c.	Mammography can detect lumps that cannot be felt by you or your doctor.	1	2	3	4	5
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5
e.	My health is too good to consider thinking that I might get breast cancer.	1	2	3	4	5
f.	If a lump is found in your breast, it is usually too late to do anything about it.	1	2	3	4	5
g.	Whenever I hear of a friend/relative or public figure getting breast cancer I realize that I could get it too.	1	2	3	4	5
h.	If I examine my own breasts regularly, I might find a lump sooner than if I wait to go for screening.	1	2	3	4	5
i.	There are so many things that could happen to me that it is pointless to think about breast cancer.	1	2	3	4	5
j.	Even though it is a good idea, I find examination of my breasts an embarrassment.	1	2	3	4	5
k.	The older I get, the more I think about the possibility of getting breast cancer.	1	2	3	4	5
1.	Going for screening has increased my worry about breast cancer.	1	2	3	4	5
m.	If I was found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5

		Not A	t All		All The Time		
B15.	How often do you worry about developing breast cancer?	1	2	3	4	5	
B16.	To what extent do any worries you have about breast cancer interfere with every day life?	1	2	3	4	5	

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the <u>first column</u>, please keep in mind the female family member at similar risk for breast cancer <u>with whom you are closest</u>. Answer the questions in the <u>second column</u> keeping in mind <u>your spouse or intimate partner</u>. If you do not have a spouse or intimate partner, please leave the second column blank. For the <u>third column</u>, please keep in mind <u>another family member or friend to whom you are closest</u>.

keer	in mind another family member	or triena to w	nom you a	
noo ₁		Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C1.	Was physically present when you needed them.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C2.	Told you what he/she did in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C3.	Did activities to help you get your mind off things.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C4 .	Told you that the things you talk about \square You are privatejust between the two of you.	s 🗆 No 🗀	Yes 🗆 No	☐ Yes ☐ No
C5.	Suggested some action you should take.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C6.	Comforted you by showing you physical affection.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C 7.	Listened to you talk about your private \Box Yo feelings.	s 🗆 No 🗀	Yes □ No	☐ Yes ☐ No
C8.	Agreed that what you want to do is right.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C 9.	Told you how he/she felt in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C10.	Let you know that he/she will always be around if you need assistance.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend	
C11. Gave you feedback on how you were doing without saying it was good or bad.	☐ Yes ☐ No	□ Yes □ No	☐ Yes ☐ No	
C12. Pitched in and helped you do things that needed to get done.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	
C13. Intruded into your personal feelings and concerns.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	
C14. Gave you unsolicited advice.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	
C15. Attempted to make unwanted contact.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	
C16. Discouraged you from discussing your \(\subseteq \text{Ye} \) feelings and concerns.	s 🗆 No 🗀 Yes 🗀 :	No 🗆	Yes 🗆 No	
C17. Minimized your worries or concerns.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	
C18. Rejected you for displaying emotional upset.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	
C19. Insisted that you remain upbeat and optimistic.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	
C20. Let you down when you were counting on him/her.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	
C21. Is there anyone in your life with whom yo back?□ yes □ no	u can share your m	ost private feeli	ings without holdi	ng
C21a. If you are married or living with a p this partner without holding back? yes no	artner , can you sh	are your most	private feelings w	ith

D1.	Have any of the events listed happened to	you in the past	six months? (Check All That Apply)
a.	You retired or were fired or laid off from work.	g. [☐ A close family member was seriously ill or injured.
b.	You were unemployed and looking fo work.	r h. [You had a marital separation or divorce.
c.	Your spouse retired or was fired or laid off from work.	i. [You had serious troubles with relatives or close friends.
d	Your spouse was unemployed and looking for work.	j . [☐ Your spouse had troubles difficulties with relatives or close friends.
e.	☐ You had problems with the police or	k . [☐ A close family member died.
٠.	court.	1.	☐ A close friend or relative died.
f.	 You got into serious financial difficulties. 	m. [☐ You were seriously ill or injured.

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		Strong		Neutral		rongly Agree
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5
E2.	It's easy for me to relax.	1	2	3	4	5
E3.	If something can go wrong for me, it will.	1	2	3	4	5
E4.	I always look on the bright side of things.	1	2	3	4	5
E5.	I'm always optimistic about my future.	1	2	3	4	5
E6.	I enjoy my friends a lot.	1	2	3	4	5
E7.	It's important for me to keep busy.	1	2	3	4	5
E8.	I hardly ever expect things to go my way.	1	2	3	4	5
E9.	Things never work out the way I want them to	1	2	3	4	5
E10.	I don't get upset too easily.	1	2	3	4	5
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5
E12.	I rarely count on good things happening to me.	1	2	3	4	5

Below is a list of words which people might use to describe themselves. You are asked to rate them <u>twice</u>. First, please indicate for each word <u>how well it describes you</u> and second, <u>how much it matters to you</u> using the following scale.

Ex	1 2 ktremely Very mucl	1 S	3 Somew	hat	Not	4 very	well	No	5 ot at a	11	
			DESC	CRIBE	S ME			<u>MATI</u>	ERS 1	O ME	
F1.	Involved in family	1	2	3	4	5	1	2	3	4	5
F2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
F3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
F4.	Being a mother	1	2	3	4	5	1	2	3	4	5
F5.	Involved in organization/volunteer work	1	2	3	4	5	1	2	3	4	5
F6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
F7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
F8.	Being a wife	1	2	3	4	5	1	2	3	4	5
F9.	Healthy	1	2	3	4	5	1	2	3	4	5
F10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
F11.	Intelligent	1	2	3	4	5	1	2	3	4	5
F12.	Able to cope	1	2	3	4	5	1	2	3	4	5
F13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
F14.	Outgoing	1	2	3	4	5	1	2	3	4	5
F15.	Independent	1	2	3	4	5	1	2	3	4	5
F16.	Realistic	1	2	3	4	5	1	2	3	4	5
F17.	Active	1	2	3	4	5	1	2	3	4	5
F18.	Loved	1	2	3	4	5	1	2	3	4	5
F19.	Caring	1	2	3	4	5	1	2	3	4	5
F20.	Depressed	1	2	3	4	5	1	2	3	4	5

In the next table, we would like you to first rate how well you think each word will describe you <u>in the future</u>. and then, indicate how important it is for you to see yourself this way <u>in the future</u>.

1	2	3	4	5
_ *	4		NI . 4	Not at all
Extremely	Very much	Somewhat	Not very well	Not at all

							73.65	OD# 4	NOTE TO	D VO	U TO
						0 T I			NT FO		
		<u>WILL DESCRIBE YOU</u>				<u>00</u>	SEE YOURSELF THIS WAY				
	I					T -	<u>IN FUTURE</u>				
G1.	Involved in family	1	2	3	4	5	1	2	3	4	5
G2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5
G5.	Involved in organization/	1	2	3	4	5	1	2	3	4	5
	volunteer work										
G 6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5
G 9.	Healthy	1	2	3	4	5	1	2	3	4	5
G10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
G11.	Intelligent	1	2	3	4	5	1	2	3	4	5
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5
G15.	Independent	1	2	3	4	5	1	2	3	4	5
G16.	Realistic	1	2	3	4	5	1	2	3	4	5
G17.	Active	1	2	3	4	5	1	2	3	4	5
G18.	Loved	1	2	3	4	5	1	2	3	4	5
G19.	Caring	1	2	3	4	5	1	2	3	4	5
G20.	Depressed	1	2	3	4	5	1	2	3	4	5

The following questions apply to persons who are <u>married or living</u> with a partner. Please complete them if you are. <u>If you are not married or living with a partner, please skip to Section I on page 13.</u>

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
Н3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
Н6	Sex relations						
H7.	Conventionality (correct or proper behavior						
H8.	Philosophy of life						
Н9.	Ways of dealing with parents or in-laws						
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never
H16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
H17.	How often do you or your mate leave the house after a fight?						
H18.	In general, how often do you think that things between your and your partner are going well?						
H19.	Do you confide in your mate?						
H20.	Do you ever regret that you married (or lived together)?						
H21.	How often do you and your partner quarrel?						
H22.	How often do you and your mate "get on each other's nerves?"						
		Every Day	Almost Every Day	Occa- sionally	Rarely	Never	

		Every Day	Almost Every Day	Occa- sionally	Rarely	Never
H23.	Do you kiss your mate?					
		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
H24.	Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
H25.	Have a stimulating exchange of ideas.						
H26.	Laugh together.						
H27.	Calmly discuss something.						
H28.	Work together on a project.						

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. (Check yes or no).
H29. Being too tired for sex. \square Yes \square No
H30. Not showing love. \square Yes \square No
H31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the statement which best describes the degree of happiness, all things considered, of your relationship.
Extremely Fairly A Little Happy Very Extremely Perfect Unhappy Unhappy Happy Happy
H32. Please check one of the following statements which best describes how you feel about the future of your relationship. I want desperately for my relationship to succeed, and would go to almost any length to see that it does. I want very much for my relationship to succeed, and will do all I can to see that it does. I want very much for my relationship to succeed, and will do my fair share to see that it does. It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed. It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going. My relationship can never succeed, and there is no more that I can do to keep the relationship going.
SECTION I
 In general, would you say your health is: □ Excellent □ Very Good □ Good □ Fair □ Poor
12. Compared to one year ago, how would you rate your health in general now?(Check one)
 ☐ Much better now than one year ago ☐ Somewhat better now than one year ago ☐ About the same as one year ago ☐ Somewhat worse now than one year ago ☐ Much worse than one year ago

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? Please mark the appropriate box to indicate your response.

		YES, limited a lot.	YES, limited a little.	NO, not limited at all.
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.			

I4. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical** health?

a.	Cut down the amo	unt of time you spent on work or other activities.
	☐ Yes	□ No
b.	Accomplished less	s than you would like.
	☐ Yes	□ No
c.	Were limited in the	e kind of work or other activities.
	☐ Yes	□ No
d.	Had difficulty perf	forming the work or other activities (for example, it took extra effort).
	☐ Yes	□ No

I5.	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?							
	a. Cut down the amo	ount of time y	ou spent on	work \square Yes	S	\square N o		
	or other activities.							
	b. Accomplished less	s than you we	ould like.		\square Yes	[□No	
	c. Didn't do work or	other activiti	ies as		☐ Yes	[□No	
	carefully as usual.							
I6.	erfered with your normal so	ocial activitie	t extent has es with famil Moderately	ly, friends, ne	eighbors, or	emotional p groups? Extremely		
I7.		in have you ghtly □ N				Extremely		
I8.	work outside the home ☐ Not at all ☐ Sli	e and housew ghtly	vork)? Moderately	□ Quite	a bit 🗆	Extremely		
I9.	These questions a during the past 4 comes closest to the the past 4 weeks:	weeks. he way you	For each have bee	question, pen feeling.	olease give How much	e the one ch of the ti	answer th me duri n	at 1g
		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time	
a.	Did you feel full of pep?							
b.	Have you been a very nervous person?							
c.	Have you felt so down in the dumps that nothing could cheer you up?							
d.	Have you felt calm and peaceful?							
e.	Did you have a lot of energy?							
f.	Have you felt downhearted and blue?							

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time	
g.	Have you been a happy person?							
h.	Did you feel tired?							
	 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? □ All of □ Most of □ A good bit of □ Some of □ A little of □ None of the time the time the time the time the time How TRUE or FALSE is each of the following statements for you? 							
		Definitely True	Mostl True		n't low	Mostly False	Definitely False	
	seem to get sick a little er than other people.	A T OUC	17.00					
	am as healthy as body I know.							
c. I wor	expect my health to get se.							
d. N	ly health is excellent.							
I12.	 In the past 6 months, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? □ YES □ NO a. If yes, there was such a two-week period, did your work or relationships suffer? □ yes □ no b. If yes, there was such a two-week period, did you get counseling or psychotherapy? □ yes □ no 							
	c. If there was su☐ yes	ch a two-wee □ no	ek period, di	d you get me	dication for	this condition	on?	
I13.	emotional problems?		nseling or	psychotherap	py or med	ication for o	depression or	

J1.	How often do you have a drink containing alcohol?						
	☐ Never ☐ Monthly or less ☐ Two to four times a month						
	☐ Two to three times a week ☐ Four or more times a week						
J2.	How many drinks containing alcohol do you have on a typical day when you are drinking? \Box 1 or 2 \Box 3 or 4 \Box 5 or 6 \Box 7 to 9 \Box 10 or more						
J3.	Have you ever felt you should cut down on your drinking? □ YES □ NO						
J4.	Have people annoyed you by criticizing your drinking? ☐ YES ☐ NO						
J5.	Have you ever felt bad or guilty about drinking? ☐ YES ☐ NO						
J6.	Have you ever taken a drink first thing in the morning to steady your nerves or get rid of a hangover? \Box YES \Box NO						
L1.	Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? <u>Check all of the statements that might apply to you</u> .						
	I would ask the dentist exactly what he was going to do.						
	I would take a tranquilizer or have a drink before going.						
	I would try to think about pleasant memories.						
	I would want the dentist to tell me when I would feel pain.						
	I would try to sleep.						
	I would watch all the dentist's movements and listen for the sound of the drill.						
	I would watch the flow of water from my mouth to see if it contained blood.						
	I would do mental puzzles in my mind.						
L2.	Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.						
	I would sit by myself and have as many daydreams and fantasies as I could.						
	I would stay alert and try to keep myself from falling asleep.						
	I would exchange life stories with the other hostages.						
	If there was a radio present, I would stay near it and listen to the bulletins about what the						
	police were doing.						
	I would watch every movement of my captors and keep an eye on their weapons.						
	I would try to sleep as much as possible.						
	I would think about how nice it's going to be when I get home.						
	I would make sure I knew where every possible exit was.						

L3.	Vividly imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off's has been made and will be announced in several days. Check all of the statements that might apply to you.
	 I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said. I would review the list of duties for my present job and try to figure out if I had fulfilled them all. I would go to the movies to take my mind off things. I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me. I would push all thoughts of being laid off out of my mind. I would tell my spouse that I'd rather not discuss my chances of being laid off. I would try to think which employees in my department the supervisor might have thought had done the worst job. I would continue doing my work as if nothing special was happening.
L4.	Vividly imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check all of the statements that might apply to you. I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were. I would make small talk with the passenger beside me. I would watch the end of the movie, even if I had seen it before. I would call for the stewardess and ask her exactly what the problem was. I would order a drink or tranquilizer from the stewardess. I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary. I would talk to the passenger beside me about what might be wrong. I would settle down and read a book or magazine or write a letter.

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

	Not at all	A little	Quite a bit	<u>Extremely</u>
K1. Suddenly scared for no reason				
K2. Feeling fearful				and the second s
K3. Faintness, dizziness, or weakness				
K4. Nervousness or shakiness inside				
K5. Heart pounding or racing				
K6. Trembling			*	
K7. Feeling tense or keyed up				
K8. Headaches				
K9. Spells of terror or panic				
K10. Feeling restless, can't sit still				
K11. Feeling low in energy-slowed down				
K12. Blaming yourself for things				
K13. Crying easily				
K14. Loss of sexual interest or pleasure				
K15. Poor appetite				
K16. Difficult falling asleep, staying asleep				
K17. Feeling hopeless about the future				
K18. Feeling blue				
K19. Feeling lonely				
K20. Feeling trapped or caught				
K21. Worrying too much about things				
K22. Feeling no interest in things				
K23. Thoughts of ending your life				
K24. Feeling everything is an effort				
K25. Feelings of worthlessness				

L1. Please indicate how much you agree with the following statements.

Ll.	Please indicate now much you agree with the ron	Strong Disagr	rly			rongly Igree
a.	If you don't have your health, you don't have anything.	1	2	3	4	5
b.	There are many things I care about more than my health.	1	2	3	4	5
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5
d.	There is nothing more important than good health.	1	2	3	4	5

Please indicate the extent to which each of the following items describes your current family.

Ticase	indicate the extent to which each of the rotto wing item	Strong Disagr				rongly Igree
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
М3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
M9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

THANK YOU VERY MUCH.

		=	





WOMEN'S HEALTH STUDY QUESTIONNAIRE

Phone Number	
Best time to reach you: Weekdays Weekday evenings Weekend days Weekend evenings Anytime	
Other:	
Is there an alternative phone number where we may reach	you

I

		1				
Today	's Date	·			ID	
Back	ground Data					
A1.	Date of Birth	MonthD	ay	_Year		
A2.	Ethnic Background:	White Hispanic Native American		Black Asian Other		
A3.	Religion:	Catholic Jewish None		Protestant Other		
	Are you currently (please Single Not married, but living in a smarriage-like relationship	teady,	□ Div	arated orced	Widowed	
A5a.	If you are currently marrie Month You	d, what was the date ear	of your c	urrent marriage?		
A5b.	Is this your first marriage?	Yes \square N	Io □			
A6.	How many children do you	ı have?				
	A6a1. Ages of DAUGH	TERS: a d	_ b _ e	c f		
	A6a2. Ages of SONS:	a d	_ b _ e	c		
	A6a. Number of children A6b. Number who are un					
A7.	Are you currently working	for pay outside the l	nome?	Yes \square	No □	
A8.	If yes, about how many ho Less than 10 10-2	ours per week are young 20 21-30	ou working	g for pay? 31-40 41 □	or more	
A9. What is the highest level of education you have completed? (Check one) Less than 9th grade Dropped out of high school Completed high school Some college Completed college Some graduate or professional training						
The Pleas	following two questions as e check the appropriate box	re optional, but we . (Check one)	e hope tha	t you will prov	ide this information.	
A10. □	What is your household's Less than \$10,000	\$10,000 to \$19,	999 999	\$20,000 to		

A11.	How many people (adults and	l children) does this in	come support?		
B1. B2.	When were you first diagnose Have your lymph nodes been Yes		Month Do Not Know		
B3.	Do you currently consider you Yes	urself in remission? No □	Do Not Know		
B4.	What treatment(s) have you re Chemotherapy Radiation Surgery	eceived for breast canc Yes Yes Yes Yes Yes Yes	er? No □ No □ No □		
B5.	Have you ever been diagnose If yes, when? Month				No □
B6.	Have you ever had any of th	ne following surgical	procedures? (Ple	ase check all	that apply).
	B6a. Lumpectomy	(Removal of lump from	n breast)		
	If yes, when?	Month Year_			
	B6bOophorecton	ny (Removal of ovarie	s)		
	If yes, when?	Month Year_			
	B6cUnilateral ma	astectomy (Removal o	f one breast)		
	If yes, when?	Month Year_			
	B6dHysterectomy	(Removal of uterus)			
	If yes, when?	Month Year_			
	B6eBilateral maste	ectomy (Removal of b	oth breasts)		
	If yes, when?	Month Year_			
B7.	Before your diagnosis of brea cancer, <u>compared to the ave</u> Much Less Lil	ast cancer, how likely of the second	circle one)	ı were to devel	op breast
B8.	Before your diagnosis of brea	ast cancer, how likely	did you think you	a were to devel	op breast
	cancer, compared to other w Much Less Lil	kelv Much	More Likely	one)	
	1	2 3 4	5		
B9.	Overall, what do you believe	your risk is of develo	ping breast cance	er again in the	near
	future? 0% 10% 20%	30% 40% 50%	60% 70%	80% 90%	100%
B10.	Overall, what do you believe	your risk is of develo	ping breast cand	er again at so	me point in
	your lifetime? 0% 10% 20%	30% 40% 50%	60% 70%	80% 90%	100%
B11.	Overall, what do you believe	your risk is of develop	oing a metasis (ca	ancer spreading	to another site)
	in the near future?	30% 40% 50%			

B12.	Overall, what	t do you	believe	e your	risk is o	f devel	oping a	metasis	at son	ne poin	<u>t in your</u>
	lifetime? 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
B13.	Overall, what			your r	isk is of	develo	ping car	icer un i	related	to your	breast
	cancer in the	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
B14.	Overall, what	do you	believe	your r	isk is of	develo	ping car	icer un i	related	to your	breast
	cancer at so	me poi	20%	30%	40%	50%	60%	70%	80%	90%	100%
B15.	A medical tes risk for develo you have been learn if your	oping a diagno cancer i	form of sed with the sed with t	breast h breas pe that	and ova t cancer runs in	rian car , would familie	you contes? (Please	runs in nsider ta ease ch	familie king th eck <u>on</u> e	es. Ever e geneti <mark>e respo</mark>	though c test to nse).
				•	the test i		-).
				•	the test,						
					he test ii		-		comes a	vailable	•
					he test,			ately.			
					her I wi		he test.				
					ke the to						
		I will	<u>definite</u>	<u>ly not</u> ta	ake the t	est.					
B16.	If you think y so? (Please	ou will check	probabl all tha	y or de t appl	finitely i	take the	test, wi	nat are y	your rea you).	sons for	doing
		To pla	n for th	e futur	e.						
		To red	luce the	uncerta	ainty.						
		To kn	ow I hav	ve to be	e more c	areful a	bout do	ing self	examin	ations a	nd
		getting	g regula	r check	tups.						
		To ma	ke deci	sions al	bout wh	ether to	get pre	ventive	surgery	•	
		To ma	ke deci	sions al	bout fan	nily plan	nning.				
		To fin	d out th	e risk tl	hat may	be trans	smitted	to my c	hildren.		
		Family	y memb	ers wai	nt me to	get test	ing.				
		Other	(describ	e)						_	
B17.	If you do not not doing so	think ye? (Ple	ou will ase che	probab eck all	ly or de	finitely pply ; s	take the	test, w	hat are	your rea	asons for 1).
		I am h	appier	not kno	wing.						
		It wou	ild be to	o upset	tting to l	earn tha	at I am a	t high r	isk for l	breast ca	ancer.
		I belie	ve I alre	eady kr	now wha	at my ris	sk for b	east car	ncer is.		
		There	would	not be 1	much I	ould do	if I fou	nd out	I was at	high ris	sk for
		breast	cancer.								
		I do n	ot feel a	ble em	otionally	to deal	l with te	sting.			
		Famil	y memb	ers do	not wan	t me to	get testi	ng.			
	•	Risk t	o my in	surance	e covera	ge.					

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the <u>first column</u>, please keep in mind a female family member who may be at risk for breast cancer <u>with whom you are closest</u>. Answer the questions in the <u>second column</u> keeping in mind <u>your spouse or intimate partner</u>. If you do not have a spouse or intimate partner, please leave the second column blank. For the <u>third column</u>, please keep in mind <u>another family member or friend to whom you are closest</u>.

		Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
<u>C1</u> .	Was physically present when you needed them.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C2.	Told you what he/she did in a similar situation.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C3.	Did activities to help you get your mind off things.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C4.	Told you that the things you talk about are privatejust between the two of you.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C5.	Suggested some action you should take.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C6.	Comforted you by showing you physical affection.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C7.	Listened to you talk about your private feelings.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C8.	Agreed that what you want to do is right.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C9.	Told you how he/she felt in a similar situation.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
C10.	Let you know that he/she will always be around if you need assistance.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
C11.	Gave you feedback on how you were doing without saying it was good or bad.	☐ Yes ☐ No	□ Yes □ No	☐ Yes ☐ No
	Pitched in and helped you do things that needed to get done.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
C13.	Intruded into your personal feelings and concerns.	☐ Yes ☐ No	□ Yes □ No	☐ Yes ☐ No
C14.	Gave you unsolicited advice.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C15.	Attempted to make unwanted contact.	☐ Yes ☐ No	□ Yes □ No	☐ Yes ☐ No
C16.	Discouraged you from discussing your feelings and concerns.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
C17.	Minimized your worries or concerns.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
C18.	Rejected you for displaying emotional upset.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
C19.	Insisted that you remain upbeat and optimistic.	☐ Yes ☐ No	□ Yes □ No	□ Yes □ No
C20.	Let you down when you were counting on him/her.	□ Yes □ No	□ Yes □ No	□ Yes □ No

C21. Is there anyone in your life with whom you can share your most private feelings without holding back?

□ Yes □ No

C21a.	feelings with this partner without holding ba		an you snare your most private
D1.	Have any of the events listed happened to y Apply)	ou in <u>th</u>	ne past six months? (Check All That
a.	You retired or were fired or laid off from work.	g.	 A close family member was seriously ill or injured.
b.	☐ You were unemployed and looking for work.	h.	You had a marital separation or divorce.
c.	☐ Your spouse retired or was fired or laid off from work.	i.	You had serious troubles with relatives or close friends.
d	Your spouse was unemployed and looking for work.	j.	Your spouse had troubles difficulties with relatives or close friends.
e.	You had problems with the police or court.	k. l.	 A close family member died. A close friend or relative died.
f.	You got into serious financial	m.	☐ You were seriously ill or injured.

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		Stroi Disa		Neutra	1	Strongly Agree
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5
E2.	It's easy for me to relax.	1	2	3	4	5
E3.	If something can go wrong for me, it will.	1	2	3	4	5
E4.	I always look on the bright side of things.	1	2	3	4	5
E5.	I'm always optimistic about my future.	1	2	3	4	5
E6.	I enjoy my friends a lot.	1	2	3	4	5
E7.	It's important for me to keep busy.	1	2	3	4	5
E8.	I hardly ever expect things to go my way.	1	2	3	4	5
E9.	Things never work out the way I want them to	1	2	3	4	5
E10.	I don't get upset too easily.	1	2	3	4	5
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5
E12.	I rarely count on good things happening to me.	1	2	3	4	5

Below is a list of words which people might use to describe themselves. You are asked to rate them <u>twice</u>. First, please indicate for each word <u>how well it describes you</u> and second, <u>how much it matters to you</u> using the following scale.

Ex	1 2 ktremely Very much	h		3 iewha	it	Not	4 very	well		Not	5 at all
			DESC	RIBE	ES M	<u>E</u>	<u>N</u>	[ATT	ERS	TO N	<u>E</u>
F1.	Involved in family	1	2	3	4	5	1	2	3	4	5
F2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
F3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
F4.	Being a mother	1	2	3	4	5	1	2	3	4	5
F5.	Involved in organization/ volunteer work	1	2	3	4	5	1	2	3	4	5
F6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
F7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
F8.	Being a wife	1	2	3	4	5	1	2	3	4	5
F9.	Healthy	1	2	3	4	5	1	2	3	4	5
F10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
F11.	Intelligent	1	2	3	4	5	1	2	3	4	5
F12.	Able to cope	1	2	3	4	5	1	2	3	4	5
F13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
F14.	Outgoing	1	2	3	4	5	1	2	3	4	5
F15.	Independent	1	2	3	4	5	1	2	3	4	5
F16.	Realistic	1	2	3	4	5	1	2	3	4	5
F17.	Active	1	2	3	4	5	1	2	3	4	5
F18.	Loved	1	2	3	4	5	1	2	3	4	5
F19.	Caring	1	2	3	4	5	1	2	3	4	5
F20.	Depressed	1	2	3	4	5	1	2	3	4	5

In the next table, we would like you to first rate how well you think each word will describe you \underline{in} the future. and then, indicate how important it is for you to see yourself this way \underline{in} the future.

1 2 3 4 5
Extremely Very much Somewhat Not very well Not at all

		WILL DESCRIBE YOU				IMPORTANT FOR YOU TO SEE YOURSELF THIS WAY IN FUTURE				<u>IS</u>	
G 1.	Involved in family	1	2	3	4	5	1	2	3	4	5
G2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5
G5.	Involved in organization/volunteer work	1	2	3	4	5	1	2	3	4	5
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5
G 9.	Healthy	1	2	3	4	5	1	2	3	4	5
G10.	Being a daughter	1	2	3	- 4	5	1	2	3	4	5
G11.	Intelligent	1	2	3	4	5	1	2	3	4	5
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5
G15.	Independent	1	2	3	4	5	1	2	3	4	5
G16.	Realistic	1	2	3	4	5	1	2	3	4	5
G17.	Active	1	2	3	4	5	1	2	3	4	5
G18.	Loved	1	2	3	4	5	1	2	3	4	5
G19.	Caring	1	2	3	4	5	1	2	3	4	5
G20.	Depressed	1	2	3	4	5	1	2	3	4	5

The following questions apply to persons who are <u>married or living with a partner</u>. Please complete them if you are. <u>If you are not married or living with a partner</u>, please skip to Section I on page 13.

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
Н3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						_
Н6.	Sex relations						
Н7.	Conventionality (correct or proper behavior						
Н8.	Philosophy of life						
Н9.	Ways of dealing with parents or in-laws			:			
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never
or hadivor termin	often do you discuss ve you considered ce, separation, or nating your onship?						
H17. How mate fight?	often do you or your leave the house after a						

				More			
		All of the time	Most of the time	often than most	Occa- sionally	Rarely	Never
H19.	Do you confide in your	time	uie unie	HIOST	Situatiy	Raiciy	140401
	mate?						
H20.	Do you ever regret that you						
	married (or lived together)?						
H21.	How often do you and your						
1100	partner quarrel?	-					
H22.	How often do you and your mate "get on each other's						
	nerves?"	ŀ					
	nerves:	1	<u> </u>				<u> </u>
		Every	Almost	Occa-]
		Day	Every Day	sionally	Rarely	Never	
H23.	Do you kiss your mate?						
		A11 - C	Man of	Some of	Many form	None of	1
		All of Them	Most of Them	Them	Very few of Them		
H24.	Do you and your mate	11011	7.7.0.1.		V		
	engage in outside interests						
	together?						İ
		Nove	Less than once a	About twice a month	About twice a week	Once a	More Often
	Have a stimulating exchange	Never	month	monu	WCCK	uay	Oltai
H25.	of ideas.						
H26.	Laugh together.						
H27.	Calmly discuss something.						
H28.		 					
HZ0.	Work together on a project.	<u> </u>	L				L
These item t	are some things couples some below caused differences of op	times agree	e and somet ere problem	imes disag	ree upon relationsl	. Indicate if only in the	either e past
	n. (Check yes or no).						
H29.	Being too tired for sex.	☐ Yes		□No			
H30.	Not showing love.	☐ Yes		□No			
	Not showing love.						
	•	nts different	degrees of		in vour	relationship	The
H31.	The following scale represer	nts different e degree of	degrees of	happiness	in your i	relationship.	The ircle the
H31. middl	The following scale represer	e degree of	happiness	happiness of most rel	ationship	os. Please c	ircle the
H31. middl staten	The following scale represent e point "happy" represents the content which best describes the content which we can be supported by the content which be supported by the content which we can be supported by the content which	e degree of legree of ha	happiness appiness, al	happiness of most rel things co	ationshij nsidered.	os. <u>Please controls</u>	ircle the tionship
H31. middl staten Extr	The following scale represent e point "happy" represents the cent which best describes the center of the fairly of	e degree of	happiness	happiness of most rel	ationshij nsidered,	os. Please c	ircle the

H32.		one of the following sur relationship.	tatements which best	describes now	you look dood! die						
		I want desperately f	or my relationship to	succeed, and $\underline{\mathbf{w}}$	<u>ould</u>						
		go to almost any len	gth to see that it does								
		I want very much fo	or my relationship to s	ucceed, and wi	<u>ll do</u>						
		all I can to see that i	t does.								
		I want very much fo	or my relationship to s	ucceed, and wi	<u>ll do</u>						
		my fair share to see	that it does.								
		It would be very nic	e if my relationship s	ucceeded, but <u>I</u>	can't						
		do much more than I am doing now to help it succeed.									
		It would be nice if it succeeded, but <u>I refuse to do any more</u>									
		than I am doing nov	v to keep the relations	hip going.							
		My relationship can	never succeed, and th	ere is no more	that I						
		can do to keep the re	elationship going.								
I1.	In general, wo	ould you say your hea	lth is:								
	☐ Excellent	☐ Very Good	\square Good	☐ Fair	□ Poor						
I2.	Compared to	one year ago, how w	ould you rate your he	alth in general	now?(Check one)						
		Much better now that	an one year ago								
		Somewhat better no	w than one year ago								
		About the same as o	ne year ago								
		Somewhat worse now than one year ago									
		Much worse than or	ne year ago								

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? Please mark the appropriate box to indicate your response. I3.

		YES, limited a lot.	YES, limited a little.	NO, not limited at all.
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.			

I4. Du or other reg	ring the past 4 weeks, have you ular daily activities as a result of	had any of the following problems with your work your physical health?			
I4a.	I4a. Cut down the amount of time you spent on work or other activities.				
	☐ Yes	\square No			
I4b.	Accomplished less than you wo	ould like.			
	☐ Yes	\square No			
I4c.	Were limited in the kind of wor	k or other activities.			
	☐ Yes	\square No			
Í I4d.	Had difficulty performing the v	ork or other activities (ie., it took extra effort).			
	☐ Yes	\square No			

15.	or othe	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?								
	I5a. Cut down the amount of time you spent on wor or other activities.				on work	□ Yes □ No				
				less than you would like.			□ Yes □			
	I5c.	Didn't do work carefully as us	or other acti			☐ Yes	[□No		
I6.	Durin problem groups	g the past 4 we ms interfered wi	eeks, to wha th your norn	t extent has nal social ac	your physicativities with t	al health or Family, frien	emotional ds, neighbor	s, or		
	8 11	☐ Not at all	☐ Slightly	☐ Mode	rately \square	Quite a bit	☐ Extrem	nely		
I7.	How n	nuch bodily pai	n have you ☐ Slightly			weeks? Quite a bit	☐ Extrem	nely		
I 8.	Durin	g the past 4 we	eeks, how m	uch did pai	n interfere w	ith your no	rmal work			
	(incluc	Inig both work o	☐ Slightly		rately	Quite a bit	☐ Extrem	nely		
I 9.	4 weel you ha	questions are above. For each que we been feeling propriate box to	estion, please . How mucl	e give the or h of the time	ne answer tha	at comes cic	sest to the w	/ay		
			All of the	Most of	A good bit	Some of	A little of	None of		
			time	the time	of the time	the time	the time	the time		
a.	Did you f	eel full of pep?								
b.	Have you nervous p	been a very errson?								
c.	in the dun	felt so down nps that ould cheer you								
d.	Have you peaceful?	felt calm and								
e.	Did you h energy?	ave a lot of								
f.	Have you downhear	felt ted and blue?								
g.	Have you person?	been a happy								
h.	Did you f	eel tired?								

I10.	During the past 4 w problems interfered w	eeks, how much ith your social a	n of the time h ctivities (like v	as your physic isiting with fric	al health or en ends, relatives,	otional etc.)?
☐ All the tin	of \square Most of	☐ A good bit o	f Som	ne of 🗆 A li	ttle of \square No	ne of e time
I11.	How TRUE or FALS	E is each of the	following sta	tements for you	1?	
		Definitely True	Mostly True	Don't Know	Mostly False	Definite False
	em to get sick a little than other people.					
	n as healthy as dy I know.					
	pect my health to get					
d. My	health is excellent.					
sad, blyou us	In the past 6 months lue, or depressed or in value, which is a sually liked to do for fur I12a. If yes, there we	which you lost aln?	ll interest in th ☐ Yes	ings like work ☐ No	or hobbies or t	hings
	☐ Yes	□ No				
	I12b. If yes, there w	as such a two-w	eek period, di	d you get coun	seling or	
	psychotherapy					
	☐ Yes	□ No				
	I12c. If there was s ☐ Yes	uch a two-week ☐ No	period, did yo	u get medicatio	n for this cond	ition?
I13.	Are you currently re-	ceiving counseli	ng or psychoth	erapy or medic	cation for depre	ession or
	emotional problems?	☐ Yes	\square No			
J1.	How often do you have	ve a drink contain	ning alcohol?			
	□ Never	☐ Monthly or l	less \square Two	to four times	a month	
	\square Two to thre	e times a week	□ For	ir or more time	s a week	
J2.	How many drinks cor ☐ 1 or 2			n a typical day o □ 7 to 9	when you are d 10 or more	rinking?
J3.	Have you ever felt yo ☐ Yes	u should cut dov	vn on your dri	nking?		
J4.	Have people annoyed ☐ Yes	you by criticizir ☐ No	ng your drinkin	ng?		
J5.	Have you ever felt ba ☐ Yes	d or guilty about ☐ No	drinking?			
J6.	Have you ever taken a hangover?	a drink first thing	g in the mornir	ng to steady you	ır nerves or get	rid of a

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

	Not at all	A little	Ouite a bit	Extremely
K1. Suddenly scared for no reason				
K2. Feeling fearful				
K3. Faintness, dizziness, or weakness				
K4. Nervousness or shakiness inside				
K5. Heart pounding or racing				
K6. Trembling				
K7. Feeling tense or keyed up				
K8. Headaches				
K9. Spells of terror or panic				
K10. Feeling restless, can't sit still				
K11. Feeling low in energyslowed down				
K12. Blaming yourself for things				
K13. Crying easily				
K14. Loss of sexual interest or pleasure				
K15. Poor appetite				
K16. Difficult falling asleep, staying asleep				
K17. Feeling hopeless about the future				
K18. Feeling blue				
K19. Feeling lonely				
K20. Feeling trapped or caught				
K21. Worrying too much about things				
K22. Feeling no interest in things				
K23. Thoughts of ending your life				
K24. Feeling everything is an effort				
K25. Feelings of worthlessness				

Which of the follows.	lowing would you do? Check all of the statements that might apply to
•	would ask the dentist exactly what he was going to do.
	would take a tranquilizer or have a drink before going.
	would try to think about pleasant memories.
	would want the dentist to tell me when I would feel pain.
	would try to sleep.
	would watch all the dentist's movements and listen for the sound of the drill
	would watch the flow of water from my mouth to see if it contained blood.
	would do mental puzzles in my mind.
Vividly imagine building. Which apply to you.	that you are being held hostage by a group of armed terrorists in a public of the following would you do? Check all of the statements that might
I	would sit by myself and have as many daydreams and fantasies as I could.
I	would stay alert and try to keep myself from falling asleep.
I	would exchange life stories with the other hostages.
If	f there was a radio present, I would stay near it and listen to the bulletins
al	bout what the police were doing.
	would watch every movement of my captors and keep an eye on their reapons.
	would try to sleep as much as possible.
	would think about how nice it's going to be when I get home.
	would make sure I knew where every possible exit was.
department at we work for the pass in several days.	that, due to a large drop in sales, it is rumored that several people in your ork will be laid off. Your supervisor has turned in an evaluation of your tyear. The decision about lay-off's has been made and will be announced Check all of the statements that might apply to you. would talk to my fellow workers to see if they knew anything about what he supervisor's evaluation of me said.
	would review the list of duties for my present job and try to figure out if I ad fulfilled them all.
I	would go to the movies to take my mind off things.
I	would try to remember any arguments or disagreements I might have had
W	with the supervisor that would have lowered his opinion of me.
I	would push all thoughts of being laid off out of my mind.
	would tell my spouse that I'd rather not discuss my chances of being laid ff.
I	would try to think which employees in my department the supervisor
n	night have thought had done the worst job.
Ţ	would continue doing my work as if nothing special was happening.

L4.	plane unexpe	ctedly goes into a deep dive and then suddenly levels off. After a short time
	You however	unces that nothing is wrong, although the rest of the ride may be rough. r, are not convinced that all is well. <u>Check all of the statements that might</u>
	apply to you.	t, are not convinced that at its week species and the species are species are species and the species are
		I would carefully read the information provided about safety features in the
		plane and make sure I knew where the emergency exits were.
		I would make small talk with the passenger beside me.
		I would watch the end of the movie, even if I had seen it before.
		I would call for the stewardess and ask her exactly what the problem was.
		I would order a drink or tranquilizer from the stewardess.
		I would listen carefully to the engines for unusual noises and would watch
		the crew to see if their behavior was out of the ordinary.
		I would talk to the passenger beside me about what might be wrong.
		I would settle down and read a book or magazine or write a letter.

L5. Please indicate how much you agree with the following statements.

		Strong Disagr				rongly Agree
a.	If you don't have your health, you don't have anything.	1	2	3	4	5
b.	There are many things I care about more than my health.	1	2	3	4	5
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5
d.	There is nothing more important than good health.	1	2	3	4	5

Please indicate the extent to which each of the following items describes your current family.

<u>a a</u>		Strong Disagr				rongly Agree
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
M3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
М9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

THANK YOU VERY MUCH.

i i		

Women's Health Study

Telephone Questionnaire
Revised 4/19/96

Introduc
returning your questionnaire. As experiences, and feelings related provided some of this information start, I would like to assure you the volunteered for the genetic studies also like to assure you that this in any questions which you do not will go on to the next question. For that is all right with youMa

Length of IW_____

Length of Edit_____

Interviewer____

~	Ā	TAT.	CE	D	ST	٨	TI	TC	
	Д	NI	. н.	ĸ		А		1.7	Ξ

1a. I understand that you (have/have not) been diagnosed with breast cancer.

Breast Cancer Positive	
Ovarian Cancer Positive	

	5. Have Not
Diagnosed	

IF R INDICATES "HAVE BEEN DIAGNOSED" TO 1a:

1b. When were you diagnosed?

DATE: _____(month/year)

1c. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not A Distre			Distr	Very essing
1	2	3	4	5

2a. I understand that you (have/have not) been diagnosed with ovarian cancer.

1. Have Been Diagnosed	5. Have No	t
---------------------------	------------	---

IF R INDICATES "HAVE BEEN DIAGNOSED" TO 2a:

2b. When were you diagnosed?

DATE:_____(month/year)

2c. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not A Distre			Distr	Very essing
1	2	3	4	5

IF R INDICATES "HAVE BEEN DIAGNOSED" TO EITHER 1a OR 2a OR BOTH:

2d. Have you ever had a second diagnosis of cancer? E.G. AFTER REMISSION, ETC.

1. Yes	5. No

IF R INDICATES "YES" TO 2d:

2e. When did you receive this second diagnosis?

D.	ATE:		(month/	year))
----	------	--	---------	-------	---

2f. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not A Distre		Distr	Very essing	
1	2	3	4	5

IF R INDICATES "YES" or "HAVE BEEN DIAGNOSED" TO 1a, 2a, OR 2d:

2g. Is your cancer currently in remission?

1. Yes	5. No

IF R INDICATES "YES" TO 2g:

2h. How long has your cancer been in remission?

2i. On a scale from 1 to 5, how distressing is it to be a member of a family that may be at risk for breast cancer?

Not A Distre			Distr	Very essing
1	2	3	4	5

A test is now available which allows women in high-risk families to find out if they (personally) have the alteration(s) of a gene (BRCA1) associated with increased risk for breast and ovarian cancer.

2j. On a scale from 1 to 5, how distressing is it to be given the opportunity to be tested for this gene?

Not A Distre			Distr	Very essing
1	2	3	4	5

2k. On a scale from 1 to 5, 1 being "not at all," and 5 being "very much," to what extent do you welcome the opportunity to be tested?

Not A All	t		Very Much	
1	2	3	4	5

21. On a scale from 1 to 5, with 1 being "not at all distressing," and 5 being "very distressing," how distressing would it be to have the test and discover that you have the altered gene that is associated with an increased risk for breast and ovarian cancer?

Not A Distre			Distr	Very essing
1	2	3	4	5

2m. Using the same scale, how distressing would it be to have the test and discover that you do not have the altered gene?

Not A Distre			Distr	Very essing
1	2	3	4	5

FOR QUESTIONS 3-5b, INDICATE THE NUMBER OF RELATIVES AFFECTED BY CANCER - ENTER ZERO FOR NO CANCER DIAGNOSIS IN A CATEGORY

		Mother	Sister(s)	Daughter(s)	First Aunt(s)	Grandmother(s)	First Cousin(s)
3.	Which of your relatives has had breast cancer?						
4.	Which of your relatives has had ovarian cancer?						
5a.	Have any of your relatives died of breast cancer?						
5b.	Have any of your relatives died of ovarian cancer?						

NOT INCLUDING GREAT-GRANDMOTHERS

DET	ATIVES	AFFECTED	\mathbf{RV}	CANCER.
кн	AIVE	APPRIL PIL	nı	L.A.N. P.R.

REPEAT THIS SECTION (QUESTIONS 0-10) FOR EACH RELATIVE R INDICATES AFFECTED BY CANCER

Start w	ith					_(relation	onship)	
Is she	e from yo	ur mot	her or y	our fath	ner's sid	le of the	family?	
Mo	ther's	Fat	her's					
	1		2]				
Whei	n was she	diagno	osed?					
DAT	E:		_(year)					
1a.	On a so	cale fro	m 1 to :	5, how	distress	ed were	you by her diagnosis?	
	Not A Distr			Dist	Very ressed		Didn't Know IF VOL.	
	1	2	3	4	5		6	
IF R	ANSWE	RS "NO	D" TO 2	2:				
	2a.	Did sh SCOR	e die of E R's B	the can	cer or s	omethin	g related to it?	
		1.	Yes	5.	No			
	IF R A	NSWE	RS "YI	ES" To	2a:	_		
		2b.	When	did she	die?	•		
			DATE	•		_(year)		
		2c.	How o	old was	she wh	en she d	lied?	
			AGE:_				_(years)	
		2d.	How o	ld were	you w	hen she	died?	
			AGE:_				_(years)	

2e. On a scale from 1 to 5, how distressed were you by this news?

Not A Distr			Distr	Very essed
1	2	3	4	5

Didn't Know IF VOL.	
6	

3. What treatment did she receive? SCORE EACH SURGERY SEPARATELY

Treatment:	1. Yes	5. No
A. Lumpectomy		
B. Unilateral Mastectomy		
C. Bilateral Mastectomy		
D. Oophorectomy (ovaries removed)		
E. Hysterectomy		
F. Chemotherapy		
G. Radiation		
H. Hormonal Therapy		
I. Immunotherapy		
J. Don't Know		
K. Other		
L. None		

IF BOTH BREASTS REMOVED IN TWO SEPARATE SURGERIES SCORE YES FOR UNILATERAL AND YES FOR BILATERAL

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

	Not At All				Very Much	Didn't Know IF VOL.
4. At the time of the illness, how (emotionally) close were you to your (relative)?	1	2	3	4	5	6

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much",

5. At the time of her illness, how aware were you of the following aspects of your (relative's) condition?

		Not at All	114 4			Very Much	Didn't Know If Vol
A.	Diagnosis	1	2	3	4	5	6
B.	Course of illness	1	2	3	4	5	6
C.	Prognosis (what could be expected)	1	2	3	4	5	6
D.	Her pain or suffering	1	2	3	4	5	6
E.	Side effects of treatment	1	2	3	4	5	6
F.	Impairment (not being able to do what she once did) and disruption of her life	1	2	3	4	5	6
G.	How involved were you in the treatment and care of your (relative)?	1	2	3	4	5	6

6. At the time of her illness, did you help care for her in any of the following ways?

	,	1. Yes	5. No
A.	Accompanied to appointments		
В.	Visited at hospital		
C.	Did chores for her		
D.	Provided comfort and emotional support		

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

		Not At All				Very Much	Didn't Know IF VOL.
7.	At that time, to what extent did you talk with her about her experience?	1	2	3	4	5	6
8.	At that time, how upsetting was her experience with cancer for you? [OVERALL]	1	2	3	4	5	6

	Much More Distant	A Little More Distant	N o Change	A Little Closer	A Lot Closer
9. At that time, how did your (relative's) illness affect your relationship with other family members? Did it make you[READ OPTIONS]	1	2	3	4	5

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

	Not At All				Very Much	Didn't Know IF VOL.
10. How much has your experience with your (relative) affected the way you think about your own risk for cancer and options for dealing with it? [CURRENTLY]	1	2	3	4	5	6

REPEAT QUESTIONS 0-10 (STARTING ON PAGE 5) FOR ANY ADDITIONAL RELATIVES

Now I'd like to find out how you keep up with new information about breast cancer (including prevention, detection, and treatment). I'm going to read you a list of sources; On a scale from 1 to 5, with 1 being "not at all" and 5 being "very much," how much do you rely on... REPEAT AS NECESSARY

		Not At All				Very Much
a.	Your OB/GYN	1	2	3	4	5
b.	Your family physician	1	2	3	4	5
c.	Another physician (Specialty)	1	2	3	4	5
d.	Family Members [WHO GAVE INFO]	1	2	3	4	5
e.	Friends [WHO GAVE INFO]	1	2	3	4	5
f.	Newspapers, television, and radio	1	2	3	4	5
g.	Popular women's magazines	1	2	3	4	5
h.	Other (specify)	1	2	3	4	5

REA	D OPTIONS	Not At All	A Little	Somewhat	A Great Deal
12.	How much do you watch for new information in the media (newspaper, magazines, television, radio)?	1	2	3	4
13.	How much do you try to avoid this information in the media?	1	2	3	. 4
14.	How much confidence do you have in the accuracy of such information in the media?	1	2	3	4

15bi. Are you aware of the gene (BRCA1) associated with increased risk for early onset breast cancer?

1. Yes	5. No
--------	--------------

IF R ANSWERS "YES" TO 15b:	Hopeful	Relieved	Anxious or Fearful	Depressed
15c. Which of the following best describes how you felt when you heard about the discovery of this gene? READ OPTIONS - R MAY CHOOSE ONLY ONE	1	2	3	4

IF R	ANSWERS "YES" TO 15b:	Not At All	A Little	Somewhat	A Great Deal
15d.	How much did you discuss this development with your mother and/or your sisters? READ OPTIONS	1	2	3	4
15e.	IF R IS MARRIED/PARTNERED: How much have you discussed this development with your (spouse/partner)? READ OPTIONS	1	2	3	4
15f.	IF R HAS CHILDREN: How much have you discussed this development with your children? READ OPTIONS	1	2	3	4

15g. IF R IS CANCER POSITIVE:

Women who are living with breast cancer report various levels of distress. How often do you feel distressed about living with breast cancer?

IF R IS CANCER NEGATIVE:

Women who are at risk for breast cancer report various levels of distress. How often do you feel distressed about your risk for breast cancer?

READ OPTIONS

Never	Rarely	Sometimes	Often	
1	2	3	4	

15h.	Thinking about your family's risk for breast cancer and your own diagnosis/risk, what has been the most distressing part?
------	---

15i. On a scale from 1 to 5, how distressing is this?

Not A Distre			Distr	Very essing
1	2	3	4	5

FOR WOMEN WITH LIVING SISTERS: SKIP IF R HAS NO LIVING SISTERS

Now I'm going to ask some questions about your relationship with your sisters.

16a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your sisters?

IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your sisters?

READ OPTIONS

Never	Rarely	Sometimes	Often	
1	2	3	4	

IF R ANSWERS "NEVER" TO 16a, DO NOT ASK 16b-d

16b. When you have these discussions, who generally initiates them?

You	Your Sisters	Equally [IF VOLUNTEERED]
1 .	2	3

16c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	Not At All A Little 1 2		A Great Deal	
1				

What is helpful to you when talking with your sisters about your risk for breast cancer? SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

		1. Yes	5. No
1.	Receiving new information.		
2.	The opportunity to express your feelings.		
3.	Receiving comfort or being taken care of.		
4.	Feeling understood.		
5.	Knowing you are not alone.		

Overall, how important is your sister's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal	
1	1 2		4	

16f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your sister's opinion?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

Considering only the positive feelings you have toward your sisters, and ignoring the negative ones, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

16h. Considering only the negative feelings you have toward your sisters, and ignoring the positive ones, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH LIVING MOTHERS:

SKIP IF R's MOTHER IS NOT LIVING

Now I am going to ask some questions about your relationship with your mother.

17a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your mother?

IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your mother?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

17b. When you have these discussions, who generally initiates them?

You	Your Mother	Equally [IF VOLUNTEERED]
1	2	3

17c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17d. What is helpful to you when talking with your mother about your risk for breast cancer? SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

		1. Yes	5. No
1.	Receiving new information.		
2.	The opportunity to express your feelings.		
3.	Receiving comfort or being taken care of.		
4.	Feeling understood.		
5.	Knowing you are not alone.		

17e. Overall, how important is your mother's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

17f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your mother's opinion?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

Considering only the positive feelings you have toward your mother, and ignoring the negative ones, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

17h. Considering only the negative feelings you have toward your mother, and ignoring the positive ones, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WHO ARE MARRIED OR LIVING WITH A PARTNER: SKIP IF R IS NOT MARRIED/PARTNERED

Now I am going to ask you some questions about your relationship with your (husband/partner).

18a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your husband/partner?

IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your husband/partner?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 18a, DO NOT ASK 18b-d

18b. When you have these discussions, who generally initiates them?

You	Your Husband/ Partner	Equally [IF VOLUNTEERED]
1	2	3

18c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

18d. What is helpful to you when talking with your husband/partner about your risk for breast cancer? SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

		1. Yes	5. No
1.	Receiving new information.		
2.	The opportunity to express your feelings.		
3.	Receiving comfort or being taken care of.		
4.	Feeling understood.		
5.	Knowing you are not alone.		

18e. Overall, how important is your husband/partner's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your (husband's/partner's) opinion?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

Considering only the positive feelings you have toward your husband/partner, and ignoring the negative ones, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

Considering only the negative feelings you have toward your husband/partner, and ignoring the positive ones, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH LIVING DAUGHTER/S: SKIP IF R HAS NO LIVING DAUGHTER/S

Now I am going to ask you some questions about your relationship with your daughter/s.

19i.	What are the ages of your daughters?	
		_

19ii. In general, do you discuss family history and risk for breast cancer with your daughter/s?

1. Yes	5. No

19e. Overall, how important is/are your daughters' opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

19f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is/are your daughter's opinion/s?

IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	1 2		4

19g. Considering only the positive feelings you have toward your daughters, and ignoring the negative ones, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

19h. Considering only the negative feelings you have toward your daughters, and ignoring the positive ones, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH CHILDREN: SKIP IF R HAS NO CHILDREN

19iii. If you should choose to obtain genetic testing, do you intend to inform your children of the results?

1. Yes	5. No	7. Undecided [IF VOLUNTEERED]
--------	--------------	--------------------------------------

FOR ALL WOMEN:	F)R	AT.	T.	W(7	IEN:
----------------	---	----	-----	----	----	---	------

20.	If you option	were to find that you were a carrier for BRCA1, the gene for increased risk of breast cancer, what s would you consider?				
٠			•			
[DON	IE]					

CSID
INTERVIEWER

Use of SCID modules

Depression.

We will be assessing current major depressive episode using the module from the SCID, A1-A5.

(add to A2, item 3: Is that a significant weight loss for you?)

(add to A2, item 4:

Insomnia:

- more than 60 minutes falling asleep

- more than 30 minutes midnight awakening

- more than 60 minutes early morning awakening

Hypersomnia:

- very early to bed

- very late rising

- extended naps (greater than 2 hours)

We then assess past major depressive episode, A12-A18.

We then asses current dysthymia, A38-A43.

Substance Use Disorders.

We assess Lifetime Alcohol Abuse/Dependence using the SCID, E1-E7.

Anxiety Disorders.

We assess current generalized anxiety disorder, F31-F35.

We then assess current mixed anxiety disorder, J5-J8.

IN THIS SECTION, MAJOR DEPRESSIVE, MANIC HYPOMANIC EPISODES, DYSTHYMIC DISORDER, MOOD DISORDER DUE TO A GENERAL MEDICAL CONDITION, SUBSTANCE-INDUCED MOOD DISORDER, AND EPISODE SPECIFIERS ARE EVALUATED. MAJOR DEPRESSIVE DISORDER AND BIPOLAR DISORDERS ARE DIAGNOSED IN MODULE D.

CURRENT MAJOR DEPRESSIVE EPISODE

Now I am going to ask you some more questions about your mood.

In the last month...

...has there been a period of time when you were feeling depressed or down most of the day nearly every day? (What was that like?)

IF YES: How long did it last? (As long as two weeks?) When did it begin?

...what about having little interest or pleasure in doing things?

IF YES: Was it nearly every day? How long did it last? (As long as two weeks?)

MDE CRITERIA

CURRENT MDE

A. Five (or more) of the following symptoms have been present during the same two week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

- (1) depressed mood most of the day, nearly every day, as indicated either by subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children and adolescents, can be irritable mood.
- (2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account of observation made by others)

NOTE: WHEN RATING THE FOLLOWING ITEMS, CODE "1" IF CLEARLY DUE TO A GENERAL MEDICAL CONDITION, MOOD-INCONGRUENT DELUSIONS OR HALLUCINATIONS ? 1 2 3 A1

IF NEITHER ITEM (1) NOR ITEM (2) IS CODED "3," GO TO *PAST MAJOR

2

A2

1

DEPRESSIVE EPISODE*,

A.12

FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS IN THE PAST MONTH (OR ELSE THE PAST TWO WEEKS IF EQUALLY DEPRESSED FOR THE ENTIRE MONTH

During this (TWO WEEK PERIOD)...

did you lose or gain any weight? (How much?) (Were you trying to lose weight?) IF NO: How was your appetite? (What about compared to your usual appetite?) (Did you have to force yourself to eat?) (Eat [less/more] than usual?) (Was that nearly every day?)	(3) significant weight le not dieting, or weight ga change of more than 5 body weight in a month decrease or increase in a nearly every day. Note: children, consider failur make expected weight garden check if:	ain (e.g., % of) or ppetite in e to gains.	1	2	3	A4 A5
how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying asleep, waking too early, OR sleeping too much? How many hours a night compared to usual? Was that nearly every night?)were you so fidgety or restless	(4) insomnia or hypersonearly every day Check if:insomniahypersomnia (5) psychomotor agitati		1	2	3	A6 A7 A8
that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	retardation nearly every (observable by others, n merely subjective feeling restlessness or being slo down)	day not gs of	1	2	3	A9
IF NO: What about the opposite talking or moving more slowly than is normal for you? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	NOTE: CONSIDER BEHAVIOR DURING THE INTERVIEW Check if:psychomotor retarpsychomotor agita					A10 A11
what was your energy like? (Tired all the time? Nearly every day?)	(6) fatigue or loss of energy nearly every day	?	1	2	3	A12
? = inadequate information	1 = absent or false 2 =	= subthreshold	3 =thre	shold or	true	

SCID (DSM-IV)	Current MDE (WHS 3/96)	Mood Episodes	•	A.3
During this time how did you feel about yourself? (Worthless?) (Nearly every day?) IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)	(7) feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick) NOTE: CODE "1" OR "2" IF ONLY LOW SELF-ESTEEM check if:worthlessinappropriate guilt	? 1 2	3	A14 A15
did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?) IF NO: Was it hard to make decisions about everyday things? (Nearly every day?)	(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others) check if:diminished ability to thinkindecisiveness	? 1 2	3	A16 A17 A18
were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself? IF YES: Did you do anything to hurt yourself?	(9) recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide NOTE: CODE "1" FOR SELF-MUTILATION W/O SUICIDAL INTENT	? 1 2	3	A19
	Check if:thoughts of own deathsuicidal ideationspecific plansuicide attempt	•		A20 A21 A22 A23
	AT LEAST FIVE OF THE ABOVE SXS [A (1-9)]ARE CODED "3" AND AT LEAST ONE OF THESE IS ITEM (1) OR (2) IF UNCLEAR, GO TO PAGE A.1	GO TO *PAST MAJOR DEPRES- SIVE EPI- SODE*, A.12	3	A24

IF UNCLEAR: Has

(depressive episode/OWN EOUIVALENT) made it hard for you to do your work, take care of things at home, or get along with other people?

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Current MDE (WHS 3/96)

2 1 A25 **GO TO *PAST** MAJOR DE-PRESSIVE **EPISODE*** A.12

Just before this began, were you physically ill?

Just before this began, were you taking any medications?

> IF YES: Any change in the amount you were taking?

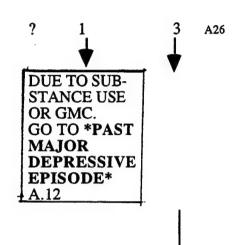
Just before this began, were vou drinking or taking any street drugs?

C. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF GENERAL MEDICAL CONDITION OR SUBSTANCE MAY BE ETIOLOGICALLY ASSOCIATED WITH DEPRESSION, GO TO *GMC/SUBSTANCE* A.43 AND RETURN HERE TO MAKE RATING OF "1" OR "3."

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease. Huntington's disease, cerebrovascular disease. metabolic and endocrine conditions [e.g., B-12 deficiency, hypothyroidism], autoimmune conditions [e.g., systemic lupus erythematosus], viral or other infections [e.g., hepatitis, mononucleosis, HIV]. and certain cancers [e.g., carcinoma of the pancreas]

Etiological substances include alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics, and other or unknown substances (e.g., steroids)





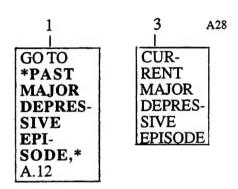
A29

(Did this begin soon after someone close to you died?)

D. Not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

3 A27 1 NOT SIM-SIMPLE BEREAVE-PLE BEREAVE-**MENT** MENT GO TO CONTINUE *PAST **BELOW MAJOR DEPRES-**SIVE EPI-SODE* A.12

MAJOR DEPRESSIVE EPISODE CRITERIA A, B, C and D are coded "3"



How many separate times have you been (depressed/OWN EQUIVALENT) nearly every day for at least two weeks and had several of the symptoms that you described, like (SXS OF WORST EPISODE)?

How old were you when (CURRENT MAJOR DEPRESSIVE EPISODE) started?

Total number of Major Depressive Episodes, including current (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)

Age at onset of Current Major Depressive Episode

Mo/Yr: ____/ ___ Age:____

IF UNCLEAR, ESTABLISH WHETHER MDE OR CANCER DX. CAME FIRST. CODE THIS INFORMATION ON SUMMARY SCORE SHEET.

PAST MAJOR DEPRESSIVE EPISODE

- -> IF NOT CURRENTLY
 DEPRESSED: Have you
 ever had a period when you
 were feeling depressed or
 down most of the day nearly
 every day? (What was that
 like?)
- I-> IF CURRENTLY
 DEPRESSED OR DOES
 NOT MEET FULL
 CRITERIA FOR PAST
 MDE: Has there been
 another time when you were
 depressed or down most of
 the day nearly every day?
 (What was that like?)

IF YES: When was that? How long did it last? (As long as two weeks?)

- -> IF PAST DEPRESSED
 MOOD: During that time,
 did you have little interest or
 pleasure in doing things you
 usually enjoyed? (What was
 that like?)
- I-> IF NO PAST DEPRESSED MOOD: What about a time when you had little interest or pleasure in doing things you usually enjoyed? (What was that like?)

IF YES: When was that? Was it nearly every day? How long did it last? (As long as two weeks?)

Have you had more than one time like that? (Which time was the worst?)

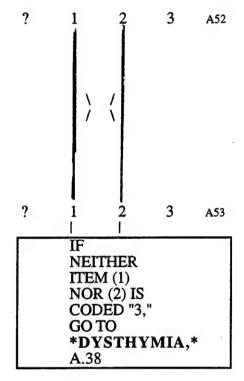
IF UNCLEAR: Have you had any times like that in the past year?

MDE CRITERIA

A. Five or more of the following symptoms have been present during the same two week period and represent a change from previous functioning; at least one of the symptoms was either (1) depressed mood or (2) loss of interest or pleasure.

(WHS 3/96)

- (1) depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children and adolescents, can be irritable mood.
- 2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account or observation made by others)



NOTE: IF MORE THAN ONE PAST EPISODE IS LIKELY, SELECT THE "WORST" ONE FOR YOUR INQUIRY ABOUT A PAST MAJOR DEPRESSIVE EPISODE. HOWEVER, IF THERE WAS AN EPISODE IN THE PAST YEAR, ASK ABOUT THAT EPISODE EVEN IF IT WAS NOT THE WORST.

SCID-I (DSM-IV) Version 2.0	Past MDE	(WHS 3/96)	Mo	od Epis	sodes	•	A.13
FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS OF THE PAST MDE YOU ARE EVALUATING. DO NOT EVALUATE A CURRENT MDE.	FOLLOW "1" IF CL DUE TO MEDICA TO MOO DELUSIO	WHEN RATING THE VING ITEMS, CODE EARLY DIRECTLY A GENERAL L CONDITION, OR D-INCONGRUENT DNS OR EINATIONS					
During that (TWO WEEK PERIOD)							
did you lose or gain any weight? (How much?) (Were you trying to lose weight?) IF NO: How was your appetite? (What about compared to your usual appetite?) (Did you have to	not dietin a change of body weig decrease of nearly even children, of make exp	icant weight loss when g, or weight gain (e.g., of more than 5% of ght in a month) or or increase in appetite ery day. Note: in consider failure to ected weight gains.	?	1	2	3	A54
force yourself to eat?) (Eat [less/more] than usual?)	Check if:	veight loss or decreased					A55
(Was that nearly every day?)	v	opetite veight gain or increased opetite					A56
how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying	(4) insom	nia or hypersomnia ry day	?	1	2	3	A 57
asleep, waking too early, OR sleeping too much? How many hours a night compared to usual?	Check if:	_ insomnia					A58
Was that nearly every night?)		hypersomnia					A59
were you so fidgety or restless that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	retardation (observab merely su	omotor agitation or n nearly every day le by others, not bjective feelings of ss or being slowed	?	1	2	3	A60
IF NO: What about the opposite talking or moving	Check if:	• • • • • • • • • • • • • • • • • • • •					A61
more slowly than is normal for you? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)		psychomotor retardation psychomotor agitation					A62
what was your energy like? (Tired all the time? Nearly every day?)	(6) fatigu energy ne	e or loss of arly every day	?	1	2	3	A63

SCID-I (DSM-IV) Version 2.0	Past MDE	(WHS 3/96)	Mood E	pisodes		A.	14
During this time how did you feel about yourself? (Worthless?) (Nearly every day?) IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)	excessive or i (which may be every day (no or guilt about NOTE: COD ONLY LOW check if: wor	DE "1" OR "2" IF SELF-ESTEEM	?	.1	2	3	A65 A65
did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?) IF NO: Was it hard to make decisions about everyday things? (Nearly every day?)	concentrate, of nearly every of subjective according to the subjective according to the check if:diminis	ed ability to think or or indecisiveness, day (either by count or as observed thed ability to think siveness	?	1	2	3	A67 A68 A69
were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself? IF YES: Did you do anything to hurt yourself?	(not just fear suicidal ideati plan, or a suic specific plan i	thoughts of death of dying), recurrent on without a specific side attempt or a for committing suicide DE "1" FOR SELF- N W/O SUICIDAL	?	1	2	3	A70
	suicion spec	ghts of own death dal ideation ific plan ide attempt					A71 A72 A73 A74

SCID-I (DSM-IV) Version 2.0	Past MDE (WHS 3/96) Mood 1	Episodes	A.15
	AT LEAST FIVE OF THE ABOVE SXS [A(1-9)] ARE CODED "3" AND AT LEAST ONE OF THESE IS ITEM (1) OR (2)	1	3 A75
IF NOT ALREADY ASKED: Has there ever been any other time when you were (depressed/own equivalent) and had even more of the symptoms than I just asked you about?		·	
-> IF YES: RETURN TO *PAST MAJOR DEPRESSIVE EPISODE* A.12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE. -> IF NO: GO TO *CURRENT DYSTHYMIA* A.38			
IF UNCLEAR: Has (depressive episode/own equivalent) made it hard for you to do your work, take care of things at home, or get along with other people?	B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.	? 1	2 3A76 CON-TINUE
IF NOT ALREADY ASKED: Has there been any other time when you were (depressed/ OWN EQUIVALENT) and it caused you even more problems than I just asked you about?		L	- .
-> IF YES: RETURN TO *PAST MAJOR DEPRESSIVE EPISODE* A.12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE			

A.38 ? = inadequate information

EPISODE.

MORE SEVERE AND/OR

CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT

-> IF NOT: GO TO *CURRENT DYSTHYMIA*

1 = absent or false

2 =subthreshold

3 =threshold or true

1

DUE TO SUB-

STANCE USE

OR GMC

A77

Just before this began, were you physically ill?

IF YES: What did the doctor say?

Just before this began, were you taking any medications?

IF YES: Any change in the amount you were taking? Did you begin a new medication?

Just before this began, were you drinking or taking any street drugs?

C. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF GENERAL MEDICAL
CONDITION OR SUBSTANCE
MAY BE ETIOLOGICALLY
ASSOCIATED WITH
DEPRESSION, GO TO
SUBSTANCE/GMC A.43.
AND RETURN HERE TO MAKE
RATING OF "1" OR "3."

REFER TO LIST OF GENERAL MEDICAL CONDITIONS AND SUBSTANCES, A.4.

IF UNKNOWN: Has there been any other time when you were depressed like this but were not using SUBSTANCE/ ill with GMC)?

-> IF YES; GO TO *PAST MAJOR DEPRESSIVE EPISODE* A.12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE.

> IF NO: GO TO *CURRENT DYSTHYMIA* A.38 PRIMARY MOOD EPISODE

CONTINUE

SCID-I (DSM-IV) Version 2.0	Past MDE (WHS 3/96)	Mood Episodes	A.17 3 A78
(Did this begin soon after someone close to you died?)	D. Not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.	SIMPLE BEREAVE- MENT	AT LEAST ONE MAJOR EPISODE NOT SIMPLE BEREAVE- MENT
IF UNKNOWN: Has there been any other time when you were depressed like this that did not occur after someone close to you died?			
-> IF YES: GO TO *PAST MAJOR DEPRESSIVE EPISODE* A12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE.		•	
-> IF NO: GO TO *CURRENT DYSTHYMIA* A.38			CON- TINUE
DISTRIMIA A.36	MAJOR DEPRESSIVE EPISODE CRITERIA A, B, C and D are coded "3"	GO TO *CUR- RENT DYSTHY- MIA*	3 A79 I PAST MAJOR DEPRES- SIVE EPISODE
How old were you when (PAST MAJOR DEPRESSIVE EPISODE) started?	Age at onset of Past Major Depressive Episode (coded above)	A.38	A80
How many separate times have you been (depressed/OWN EQUIVALENT) nearly every day for at least two weeks and had several of the symptoms that you described, like (SXS OF WORST EPISODE)?	Total number of Major Depressive Episodes, including current (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)		A81
	1 C-1 2	2 ماليان مساله بـ 2 ماليان	shald an tops

Episodes	A.18
spisones	73.10

SCID-I (DSM-IV) Version 2.0

Past MDE (WHS 3/96)

Mood Episodes

IF UNKNOWN: How old were you when first started having (SXS OF MDE)?

Age of onset of first Major Depressive Episode (CODE 99 IF UNKNOWN)

Mo./Yr.:____/__ Age:____

ESTABLISH WHETHER MDE OR CANCER DX. CAME FIRST. CODE THIS INFORMATION ON SUMMARY SCORE SHEET.

DYSTHYMIC DISORDER (CURRENT ONLY)

-> IF NO MAJOR DEPRESSIVE EPISODE IN THE PAST TWO YEARS: For the past couple of years, have you been bothered by depressed mood most of the day, more days than not? (More than half the time?)

IF YES: What was that like?

-> IF CURRENT MAJOR **DEPRESSIVE EPISODE: Let's** review when you first had most of the symptoms of (CURRENT MAJOR DEPRESSIVE EPISODE). For the two years prior to (BEGINNING DATE), were you bothered by depressed moods, most of the day, more days than not? (More than half the time?)

-> FOR A PAST MAJOR DEPRESSIVE EPISODE **DURING THE PAST TWO** YEARS: Let's review when you first had most of the symptoms of FIRST MET CRITERIA FOR (PAST MAJOR DEPRESSIVE EPISODE) and the point at which you no longer had most of the symptoms. Since the (DATE OF NO LONGER MEETING CRITERIA), have you still been bothered by depressed mood, so that you have been depressed for most of the day, more days than not?

> IF YES: For the two years prior to (DATE OF **BEGINNING OF PAST** MAJOR DEPRESSIVE EPISODE), were you bothered by depressed mood, most of the day, more days than not? (More than half the time?)

DYSTHYMIC DISORDER CRITERIA

A. Depressed mood (or can be irritable mood in children and adolescents) for most of the day, for more days than not, as indicated either by subjective account or observation made by others, for at least two years (one year for children and adolescents)

?	1	2	3	A163
	GO TO *ALCO	HOL		
	USE DISOR			
	E.1	DEKS.		

FIRST MET CRITERIA FOR CURRENT MAJOR **DEPRESSIVE EPISODE** (see A.5):

Mo/Yr: ____/ ___ Age: ____

PAST MAJOR DEPRESSIVE EPISODE (see A.17):

Mo/Yr: ____/ ___ Age: ____

NO LONGER MET CRITERIA FOR PAST MAJOR DEPRESSIVE EPISODE IN PAST TWO YEARS: Mo/Yr: ____/ ___ Age: ____

NOTE: CODE "1" IF NORMAL MOOD FOR AT LEAST TWO

MONTHS AT A TIME

A172

A173

3

How long have you been feeling this way? (When did this begin?)

COMPARE ONSET OF DYSTHYMIC SXS WITH DATES OF PAST MAJOR **DEPRESSIVE EPISODES TO** DETERMINE IF THERE WERE ANY MAJOR DEPRESSIVE **EPISODES IN FIRST TWO** YEARS OF DYSTHYMIC DISORDER.

D. No major depressive episode during the first two years of disturbance (one year for children and adolescents); i.e., not better accounted for by chronic Major Depressive Disorder in partial remission.

Dysthymic Disorder

2 GO TO *ALCOHOL **USE DIS-**ORDERS* E.1

Age at onset of current Dysthymic Disorder (CODE 99 IF UNKNOWN)

IF MAJOR DEPRESSIVE **EPISODE PRECEDED** DYSTHYMIC SXS: Now I want to know whether you got completely back to your usual self after that (MAJOR DEPRESSIVE EPISODE) you had (DATE), before this long period of being mildly depressed? (Were you back to your usual self for at least two months?)

Note: There may have been a previous Major Depressive Episode provided there was a full remission (no significant signs or symptoms for two months) before development of the Dysthymic Disorder. In addition, there may be superimposed episodes of Major Depressive Disorder, in which case both diagnoses may be given.

NOTE: CODE "3" IF NO PAST MAJOR DEPRESSIVE EPISODES OR IF MAJOR DEPRESSIVE EPISODES WERE NOT PRESENT DURING THE FIRST TWO YEARS OR IF THERE WAS AT LEAST A TWO MONTHS PERIOD WITHOUT SYMPTOMS PRECEDING THE ONSET.

E. Has never had a Manic Episode or an unequivocal Hypomanic Episode.

F. Does not occur exclusively during the course of a chronic psychotic disorder, such as Schizophrenia or Delusional Disorder.

NOTE: CODE "3" IF NO CHRONIC PSYCHOTIC DISORDER OR IF NOT SUPERIMPOSED ON A CHRONIC PSYCHOTIC DISORDER.

1 A174 GO TO *ALCOHOL USE **DISORDERS*** E.1 3 1 A175 GO TO NOT SUPER-*ALCO-HOL USE **IMPOSED DISORDERS*** $\mathbf{E}.1$ CON-TINUE

? = inadequate information

1 = absent or false

2 =subthreshold

3 =threshold or true

DUE TO SUBSTANCE

GO TO

E.1

1

USE OR GMC

*ALCOHOL

USE DIS-

ORDERS*

A176

3

Just before this began, were you physically ill?

> IF YES: What did the doctor say?

Just before this began, were you taking any medications?

> IF YES: Any change in the amount you were taking? Did vou begin a new medication?

Just before this began, were you drinking or using any street drugs? G. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

Dysthymic Disorder

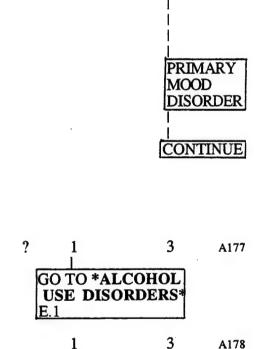
IF GENERAL MEDICAL CONDITION OR SUBSTANCE MAY BE ETIOLOGICALLY ASSOCIATED WITH DEPRESSION, GO TO *SUBSTANCE/GMC* A.43 RETURN HERE AND MAKE RATING OF "1' OR "3"

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease, Huntington's disease, cerebrovascular disease, metabolic and endocrine conditions (e.g., B-12 deficiency, hypothyroidism), autoimmune conditions (e.g., systemic lupus erythematosus), viral or other infections (e.g., hepatitis, mononucleosis, HIV), and certain cancers (e.g. carcinoma of the pancreas)

Etiological substances include: alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics, and other known or unknown substances (e.g., steroids).

H. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

DYSTHYMIC DISORDER CRITERIA A, B, C, D, E, F, AND H ARE CODED "3"



IF DYSTHYMIC DISORDER Indicate specifier:

1- Early Onset: onset before age 21

2- Late Onset: onset age 21 or older

Specifier:

GO TO

E.1

*ALCOHOL

USE DIS-

ORDERS*

A179

DYS-

THYMIC DIS-

ORDER

IF UNCLEAR: How much do

with your life?

your depressed feelings interfere

?

GMC/SUBSTANCE CAUSING MOOD/ANXIETY SYMPTOMS

MOOD/ANXIETY DISORDER DUE TO A GENERAL MEDICAL CONDITION

MOOD/ANXIETY DISORDER DUE TO A GENERAL MEDICAL CRITERIA

IF SYMPTOMS NOT TEMPORALLY ASSOCIATED WITH A GENERAL MEDICAL CONDITION, CHECK HERE AND GO TO *SUBSTANCE INDUCED MOOD DISORDER*, A45.

[FOR ANXIETY]

A187

A188

A190

CODE BASED ON INFORMATION ALREADY OBTAINED.

A. Prominent and persistent disturbance in mood/anxiety characterized by the following:

(1) depressed mood or markedly diminished interest or pleasure in all, or almost all, activities [FOR MOOD]

? 1 3 A189 (2) prominent anxiety, panic attacks, obsession or compulsions

1

2

3

3

Do you think your (MOOD/ ANXIETY SXS) were in any way related to your (COMORBID GENERAL MEDICAL CONDITION)?

IF YES: Tell me how.

(Did the [MOOD/ANXIETY SXS] start or get much worse only after **ICOMORBID GENERAL** MEDICAL CONDITION began?)

> IF YES AND GMC HAS RESOLVED: Did the (MOOD/ANXIETY SXS) get better once the (COMORBID GENERAL MEDICAL CONDITION) got better?

B./C. There is evidence from the history, physical examination, or laboratory findings that the disturbance is the direct physiological consequence of a general medical condition and the disturbance is not better accounted for by another mental disorder (e.g., Adjustment Disorder With Depressed Mood, in response to the stress of having a general medical condition).

THE FOLLOWING FACTORS SHOULD BE CONSIDERED AND SUPPORT THE CONCLU-SION THAT THE GMC IS ETIO-LOGIC TO THE MOOD/ANXIETY SXS:

- 1) THERE IS EVIDENCE FROM THE LITERATURE OF A WELL-ESTABLISHED ASSOCIATION BETWEEN THE GMC AND MOOD/ANXIETY SYMPTOMS.
- 2) THERE IS A CLOSE TEMPORAL RELATIONSHIP BETWEEN THE COURSE OF THE MOOD/ANXIETY SXS AND THE COURSE OF THE GENERAL MEDICAL CONDI-TION.

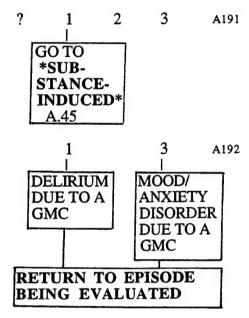
? 2 1 GO TO *SUB-**STANCE** INDUCED* 4.45

Mood Episodes

- 3) THE MOOD/ANXIETY SYMP-TOMS ARE CHARACTERIZED BY UNUSUAL PRESENTING FEATURES (E.G., LATE AGE AT ONSET)
- 4) THE ABSENCE OF ALTERNATIVE EXPLANATIONS (E.G., MOOD/ANXIETY SYMPTOMS AS A PSYCHOLOGICAL REACTION TO THE GMC)

IF UNCLEAR: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

- E. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning
- D. The disturbance does not occur exclusively during the course of Delirium.



SCID-I (DSM-IV) Version 2.0	Substance-Induced (WHS	3/96) Mod	od Episode	S		A.45
SUBSTANCE -INDUCED MOOD/ANXIETY DISORDER	SUBSTANCE-IND MOOD/ANXIETY DISORDER CRITE	RIA C	EPISODE E Current MD Past MDE		VALU	ATED: A.1 A.12
IF SYMPTOMS NOT TEMPORA LY ASSOCIATED WITH SUB- STANCE, CHECK HERE AND RETURN TO EPISODE BE ING EVALUATED.			Oysthymia Current GA MAD	D		A.38 F.31 J.8
CODE BASED ON INFORMATION ALREADY OBTAINED.	A. A prominent and per disturbance in mood/and characterized by the following	xiety				
	(1) depressed mood or a diminished interest or p all, or almost all, activit MOOD].	leasure in	1	2	3	A194
	(2) prominent anxiety, attacks, obsession or co [FOR ANXIETY]		1	2	3	A195
IF NOT KNOWN: When did the (MOOD/ANXIETY SYMPTOMS) BEGIN? (Were you already (SUBSTANCE) or had you just stopped or cut your use?	B. There is evidence from history, physical examination and the symptoms in A conduction of th	nation, or either leveloped h of T cation use	1 NOT SUBS NDUCED I O EPISOD VALUATE	RETURI E BEIN	V	A196
Do you think your (MOOD/ ANXIETY SXS) are in any way related to your (SUBSTANCE USE)? IF YES: Tell me how.	C. The disturbance is n accounted for by a Mood Disorder that is not substinduced. Evidence that symptoms are better account by a Mood Disorder that substance-induced might	d/Anxiety stance- the In ounted for T t is not E	1 IOT SUBS' NDUCED I O EPISOD VALUATE	RETURI E BEIN		A197
ASK ANY OF THE FOLLOWING QUESTIONS AS NEEDED TO RULE OUT A NON-SUBSTANCE-INDUCED ETIOLOGY:						
IF UNKNOWN: Which came first the (SUBSTANCE USE) or the (MOOD/ANXIETY SYMPTOMS)?	precede the onset of the					
IF UNKNOWN: Have you had a period of time when you stopped using (SUBSTANCE)?	2) the mood/anxiety syn persist for a substantial p time (e.g., about a mont cessation of acute withd severe intoxication)	period of h after the				
? = inadequate information	1 = absent or false 2	= subthreshold	3 =th	nreshold	or true	

IF YES: After you stopped using (SUBSTANCE) did the (MOOD/ANXIETY SYMPTOMS) get better?

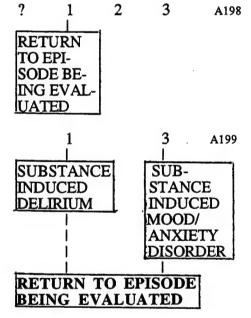
IF UNKNOWN: How much of (SUBSTANCE) were you taking when you began to have (MOOD/ANXIETY SYMPTOMS)?

IF UNKNOWN: Have you had any other episodes of (MOOD/ANXIETY SYMPTOMS)?

IF YES: How many? Were you taking (SUBSTANCES) at those times?

IF UNKNOWN: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

- 3) the mood symptoms are substantially in excess of what would be expected given the character, duration, or amount of the substance used
- 4) There is evidence suggesting the existence of an independent non-substance-induced Mood/Anxiety Disorder (e.g., a history of recurrent non-substance-related Major Depressive Episodes).
- E. The symptoms cause clinically significant distress or impairment in social, occupational, or their important areas of functioning.
- D. The disturbance does not occur exclusively during the course of Delirium.



E. SUBSTANCE USE DISORDERS

ALCOHOL USE DISORDERS (LIFETIME)

IF QUESTIONS J3, J4, J5, AND J6 FROM WHS QUESTIONNAIRE ANSWERED "NO," CHECK HERE _____ AND SKIP TO *GENERAL ANXIETY DISORDER*, F.31.

IF SCREENERS NOT USED OR IF ANY OF J3, J4, J5, OR J6 FROM WHS QUESTIONNAIRE ANSWERED "YES." CONTINUE:

What are your drinking habits like? (How much do you drink?)

When in your life were you drinking the most? (How long did that period last?)

During that time...

how often were you drinking?

what were you drinking? how much?

RECORD DATE OF HEAVIEST USE AND DESCRIBE PATTERN:

During that time...

did your drinking cause problems for you?

did anyone object to your drinking?

IF ALCOHOL DEPENDENCE SEEMS
LIKELY, CHECK HERE ____ AND
SKIP TO *ALCOHOL DEPENDENCE*,
E.4.

OTHERWISE, CONTINUE WITH *ALCOHOL ABUSE*
ON NEXT PAGE.

E1

ALCOHOL ABUSE CRITERIA *LIFETIME ALCOHOL ABUSE* A. A maladaptive pattern f Let me ask you a few more questions substance use leading to clinically about your drinking habits. significant impairment or distress, as manifested by one (or more) of the following occurring within a twelve month period: E2 ? 1 2 3 Have you ever been intoxicated or high (1) recurrent alcohol use resulting or very hung over while you were doing in a failure to fulfill major role something important, like being at school obligations at work, school, or home (e.g., repeated absences or or work, or taking care of children? poor work performance related to IF NO: What about missing something alcohol use; alcohol-related important, like staying away from school absences, suspensions, or expulsions from school; neglect of or work or missing an appointment children or household) because you were intoxicated, high, or very hung over? IF YES TO EITHER OF ABOVE: How often? (Over what period of time?) E3 9 1 Did you ever drink in a situation in which (2) recurrent alcohol use in it might have been dangerous to drink at situations in which it is physically all? (Did you ever drive while you were hazardous (e.g., driving an really too drunk to drive?) automobile or operating a machine when impaired by alcohol use) IF YES AND UNKNOWN: How often? (Over what period of time?) ? 1 2 3 (3) recurrent alcohol-related legal Has your drinking gotten you into trouble with the law? problems (e.g., arrests for alcoholrelated disorderly conduct) IF YES AND UNKNOWN: How often? (Over what period of time?) E5 1 IF NOT ALREADY KNOWN: Has your (4) continued alcohol use despite drinking caused you problems with other having persistent or recurrent social or interpersonal problems people, such as family members, friends, or people at work? (Have you caused or exacerbated by the effects of alcohol (e.g., bad ever gotten into physical fights or had arguments with spouse about bad arguments about your drinking?) consequences of intoxication,

physical fights)

time?)

IF YES: Did you keep on drinking

anyway? (Over what period of

E6

AT LEAST ONE "A" ITEM CODED "3"

?

3

IF NO POSSIBILITY OF PHYSIOLOGICAL DEPENDENCE OR COMPULSIVE USE, GO TO *GENERALIZED ANXIETY DISORDER,* F.31. OTHERWISE, CONTINUE ASKING ABOUT DEPENDENCE, E.4.

ALCOHOL
ABUSE.
CONTINUE
ASKING
ABOUT
DEPENDENCE
E.4

ALCOHOL DEPENDENCE

ALCOHOL DEPENDENCE CRITERIA

I'd now like to ask you some more questions about your drinking habits.

A maladaptive pattern of alcohol use, leading to clinically significant impairment or distress, as manifested by three (or more) of the following occurring at any time in the same twelve month period:

NOTE: CRITERIA FOR ALCOHOL DEPENDENCE ARE NOT IN DSM IV ORDER

Have you often found that when you started drinking you ended up drinking more than you were planning to?

IF NO: What about drinking for a much longer period of time than you were planning to?

Have you tried to cut down or stop drinking alcohol?

IF YES: Did you ever actually stop drinking altogether?

(How many times did you try to cut down or stop altogether?)

IF NO: Did you want to stop or cut down? (Is this something you kept worrying about?)

Have you spent a lot of time drinking, being high, or hung over?

Have you had times when you would drink so often that you started to drink instead of working or spending time at hobbies or with your family or friends? (3) alcohol is often taken in larger amounts OR over a longer period than was intended

(4) there is a persistent desire OR unsuccessful efforts to cut down or control substance use

(5) a great deal of time is spent in activities necessary to obtain alcohol, use alcohol, or recover from its effects

(6) important social, occupational, or recreational activities given up or reduced because of alcohol use

? 1 2 3

? 1 2 3 E

? 1 2 3

1 2 3 E10

...or feeling anxious?

feeling, or hearing things that weren't really there?)

IF NO: Have you ever started the day with a drink, or did you often drink to keep yourself from getting the shakes or becoming sick?

(b) alcohol (or a substance from the sedative/ hypnotic/anxiolytic class)

auditory hallucination or

taken to relieve or avoid withdrawal symptoms

illusions

E15

E16

E18

IF UNKNOWN: When did (SXS CODED "3" ABOVE) occur? (Did they all happen around the same time?)

AT LEAST THREE "A" ITEMS CODED "3" AND ITEMS OCCURRED WITHIN THE SAME TWELVE (12) MONTH PERIOD

Indicate if:
1 - With Physiological Dependence
(current evidence of tolerance or withdrawal)
2- Without Physiological Dependence
(no current evidence of tolerance or withdrawal)
GO TO DEPENDENCE CHRONOLOGY, E.7

IF ALCOHOL ABUSE QUESTIONS (PAGES E.1-E.3) HAVE <u>NOT</u> YET BEEN ASKED, GO TO PAGE E.1 AND CHECK FOR ABUSE.

IF ABUSE QUESTIONS HAVE BEEN ASKED AND ABUSE IS PRESENT, CODE "3"; OTHERWISE, IF QUESTIONS HAVE BEEN ASKED AND ABUSE IS NOT PRESENT, GO TO *GENERALIZED ANXIETY DISORDER F.31.

GO TO
*GENERALIZED
ANXIETY
DISORDER* F.31

ALCOHOL DEPENDENCE

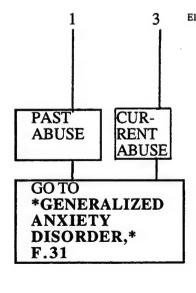
How old were you when you first had (ABUSE SXS CODED "3")?

Age at onset of Alcohol Abuse (CODE 99 IF UNKNOWN)

IF UNCLEAR: During the past month, have you had anything at all to drink?

IF YES: Tell me more about it. (Has your drinking caused you any problems?)

Criteria for Alcohol Abuse met at any time in past month



E21

E22

3

1

CHRONOLOGY FOR DEPENDENCE

How old were you when you first had (LIST OF ALCOHOL DEPENDENCE OR ABUSE SXS CODED "3")?

Age at onset of Alcohol Dependence or Abuse (CODE 99 IF UNKNOWN)

IF UNCLEAR: During the past month, have you had anything at all to drink?

IF YES: Tell me more about it. (Has your drinking caused you any problems?)

Full criteria for Alcohol
Dependence met at any time in past
month (or never had a month
without symptoms of Dependence
or Abuse since onset of
Dependence)



SEVERITY SPECIFIERS FOR DEPENDENCE

NOTE SEVERITY OF DEPENDENCE FOR WORST WEEK OF PAST MONTH (Additional questions about the effect of alcohol on social and occupational functioning may be necessary.)

1-Mild: Few, if any, symptoms in excess of those required to make

the diagnosis, and the symptoms result in no more than mild impairment in occupational functioning or in usual social activities or relationships with others (or criteria met for Dependence in the past and some current problems)

Dependence in the past and some current problems).

Symptoms or functional impairment between "mild" and

"severe."

3-Severe: Many symptoms in excess of those required to make the

diagnosis, and the symptoms markedly interfere with occupational functioning or with usual social activities or

relationships with others.

GO TO *GENERALIZED ANXIETY DISORDER, F.31*

2-Moderate:

F136

F137

*GENERALIZED ANXIETY **DISORDER*** (CURRENT ONLY)

GENERALIZED ANXIETY DISORDER CRITERIA

In the past six months, was there a period when you were particularly nervous or anxious?

Do you also worry a lot about bad things that might happen?

> IF YES: What do you worry about?(How much do you worry about **IEVENTS OR** ACTIVITIES])

A. Excessive anxiety and worry (apprehensive expectation). occurring more days than not for at least six months, about a number of events or activities (such as work or school performance)

1 2 3 F135 GO TO *MIXED ANXIETY DISOR-**DER.*** J.5

During the last six months, would you say that you have been worrying (more days than not?)

When you're worrying this way, do you find that you can't stop vourself?

B. The person finds it difficult to control the worry

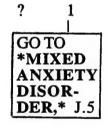
2 3 1 GO TO *MIXED ANXIETY DISOR-**DER,*** J.5

2

3

When did this anxiety start? COMPARE ANSWER WITH ONSET OF MOOD OR PSYCHOTIC DISORDER.

F(2). Does not occur exclusively during the course of a Mood Disorder, Psychotic Disorder, or a Pervasive Developmental Disorder



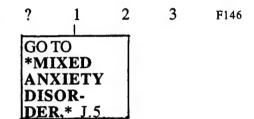
SCID Version 2.0 (For DSM-IV)	GAD	(WHS 3/96)	Anxiety I	Disorder	S.		F.32
Now I am going to ask you some questions about other symptoms that often go along with being nervous.	associate followin least son	enxiety and worry are bed with at least three of to g such symptoms (with the symptoms present for the past seems.)	at r				
Thinking about those periods in the past six months when you're feeling nervous or anxious							
do you often feel physically restless can't sit still?	(1) restle	essness or feeling keyed edge	d ?	1	2	3	F138
do you often feel keyed up or on edge?							
do you often tire easily?	(2) being	g easily fatigued	?	1	2	3	F139
do you have trouble concentrating or does your mind go blank?	(3) diffication mind goi	culty concentrating or ng blank	?	1	2	3	F140
are you often irritable?	(4) irrital	bility	?	1	2	3	F141
are your muscles often tense?	(5) musc	cle tension	?	1	2	3	F142
do you often have trouble falling or staying asleep?	falling or	disturbance (difficulty staying asleep, or restling sleep)		1	2	3	F143
	AT LEAS	ST THREE "C" SXS A "3"	GO *MI ANI DIS	1 TO IXED XIETY OR- R,* J.5		3	F144

CODE BASED ON PREVIOUS INFORMATION.

D. The focus of the anxiety and worry is not confined to the features of another Axis I Disorder, e.g. being embarrassed in public (as in Social Phobia), being contaminated (as in Obsessive-Compulsive Disorder), being away from home or close relatives (as in Separation Anxiety Disorder), gaining weight (as in Anorexia Nervosa), or having a serious illness (as in Hypochondriasis), and is not part of Posttraumatic Stress Disorder.

? 1 3 F145
GO TO
*MIXED
ANXIETY
DISORDER,* J.5

IF UNCLEAR: What effect has the anxiety, worry, or (PHYSICAL SYMPTOMS) had on your life? (Has it made it hard for you to do your work or be with your friends?) E. The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning



Just before you began having this anciety, were you taking any drugs, stimulants or medicines?

(How much coffee, tea, or cola do you drink a day?)

Just before these problems began, were you physically ill?

IF YES: What did the doctor say?

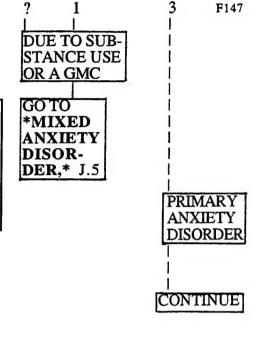
F. Not due to the direct psychological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

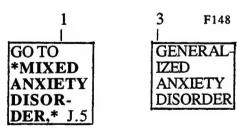
IF A GENERAL MEDICAL
CONDITION OR SUBSTANCE
MAY BE ETIOLOGICALLY
ASSOCIATED WITH THE
ANXIETY, GO TO
SUBSTANCE /GMC, A.43
RETURN HERE TO MAKE
RATING OF "1" OR "3".

Etiological general medical conditions include: hyper- and hypo-thyroidism, hypoglycemia, hyperparathyroidism, pheochromocytoma, congestive heart failure, arrhythmias, pulmonary embolism, chronic obstructive pulmonary disease, B-12 deficiency, porphyria, CNS neoplasms, vestibular dysfunction, encephalitis.

Etiological substances include: intoxicants with central nervous stimulants (e.g., cocaine, amphetamines, caffeine) or cannabis, hallucinogens, PCP, or alcohol, or withdrawal from central nervous system depressants (e.g., alcohol, sedatives, hypnotics) or cocaine

GENERALIZED ANXIETY CRITERIA A,B,C,D,E,AND F ARE CODED "3"





F149

CHRONOLOGY OF GENERALIZED ANXIETY DISORDER

INDICATE CURRENT SEVERITY:

Mild: Few, if any, symptoms in excess of those required to make the diagnosis are present, and symptoms result in no more than minor impairments in social or occupational functioning.

Anxiety Disorders

- Moderate: Symptoms or functional impairment between "mild" and "severe" are present. 2--
- Severe: Many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in social or occupational functioning.

AGE AT ONSET

IF UNKNOWN: How old were you when you first started having (SXS OF GAD)?

Age at onset of Generalized Anxiety Disorder (CODE 99 IF UNKNOWN)

GO TO *MIXED ANXIETY DISORDER* J.5.

MAD

MIXED ANXIETY DISORDER CRITERIA (APPENDIX CATEGORY)

IF: CRITERIA HAVE EVER BEEN MET FOR MAJOR DEPRESSIVE DISORDER, DYSTHYMIC DISORDER, PANIC DISORDER, OR GENERALIZED ANXIETY DISORDER, CHECK HERE___ AND END SCID INTERVIEW.

IF: CRITERIA ARE CURRENTLY MET FOR ANY OTHER ANXIETY OR MOOD DISORDER (INCLUDING AN ANXIETY DISORDER OR MOOD DISORDER IN PARTIAL REMISSION), CHECK HERE____AND END SCID INTERVIEW.

AND END SCID INTERVIEW.						
During the past month, have you been feeling badthat is depressed or anxious for most of the time?	A. Persistent or recurrent dysphoric mood lasting at least one month.	?	1 	2	3	J2 0
During those times when you're feeling bad	B. The dysphoric mood is accompanied by at least 1 month of four (or more) of the following symptoms:					
	NOTE: FOR EACH OF THE FOLLOWING, MAKE SURE THE SYMPTOM LASTED AT LEAST 1 MONTH					
have you had trouble concentrating or does your mind go blank?	(1) difficulty concentrating or mind going blank	?	1	2	3	J2 1
have you had trouble sleeping?	(2) sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)	?	1	2	3	J22
have you felt like you were tired all the time or that your energy was low?	(3) fatigue or low energy	?	1	2	3	J23
have you felt irritable or cranky?	(4) irritability	?	. 1	2	3	J 24
did you worry a lot about things?	(5) worry	?	1	2	3	J2 5
did you find yourself crying over little things?	(6) easily moved to tears	?	1	2	3	J26
have you been watchful or on guard even when there is no reason to be?	(7) hypervigilance	?	1	2	3	32 7

SCID-I (DSM-IV) Version 2.0 MAD	(WHS 3/96)				J.6	j
when looking ahead, were you expecting the worst?	(8) anticipating the worst	?	1	2	3 ·	J28
did you feel hopeless about the future?	(9) hopeless (pervasive pessimism about the future)	?	1	2	3	J2 9
did you feel down on yourself or that you were worthless?	(10) low self-esteem or feelings of worthlessness	?	1	2	3	J30
	AT LEAST FOUR "B" SYMPTOMS CODED "3"	? 	1 I DONE		3	J31
IF UNCLEAR: How much did these bad feelings interfere with your life?	C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.	?	1 	2	3	J32

Just before you began having these symptoms, were you taking any drugs, stimulants or medicines?

(How much coffee, tea, or cola do you drink a day?)

Just before these problems began, were you physically ill? (What did the doctor say?)

D. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF A GENERAL MEDICAL
CONDITION OR SUBSTANCE
MAY BE ETIOLOGICALLY
ASSOCIATED WITH THE
ANXIETY, GO TO
GMC/SUBSTANCE, A.43
AND RETURN HERE TO MAKE
RATING OF "1" OR "3."

Etiological general medical conditions include: hyper- and hypo-thyroidism, hypoglycemia, hyper-parathyroidism, pheochromocytoma, congestive heart failure, arrythmias, pulmonary disease, pneumonia, hyperventilation, B-12 deficiency, porphyria, CNS neoplasms, vestibular dysfunction, encephalitis.

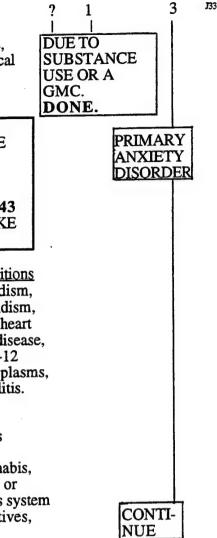
Etiological substance include: intoxication with central nervous stimulants (e.g., cocaine, amphetamines, caffeine) or cannabis, hallucinogens, PCP, or alcohol, or withdrawal from central nervous system depressants (e.g., alcohol, sedatives, hypnotics) or from cocaine.

E. All of the following:

(1) Has never met criteria for Major Depressive Disorder, Dysthymic disorder, Panic Disorder, or Generalized Anxiety Disorder.

(2) Does not currently meet criteria for any other Anxiety or Mood Disorder (including an Anxiety or Mood Disorder in partial remission)

(3) Not better accounted for by any other mental disorder



DONE

3

J34

CRITERIA A, B, C, D, AND E ARE CODED "3"

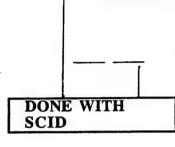
3 ISS I MIXED ANXIETY DEPRES-SIVE DIS-ORDER

J36

AGE AT ONSET

IF UNKNOWN: How old were you when you first started having (SXS OF MAD)?

Age at onset of Mixed Anxiety Depressive Disorder (CODE 99 IF UNKNOWN)



|--|--|--|--|--|--|--|





WOMEN'S HEALTH STUDY

Interim Questionnaire

As you may already know, there are two components to this breast cancer research--a study of the biology of genetics, which is now located at the University of Pennsylvania (previously it was at the University of Michigan) and a study of the personal and social aspects of genetic testing which is located at the University of Michigan. This questionnaire is part of the study of personal and social aspects. Some of these questions will be familiar. We are asking them again to learn more about how feelings and attitudes change over time.

If you have any questions about this questionnaire or research, please feel free to call me at 313-998-6560. For questions about the genetic testing component, you may call Kathleen Calzone at the University of Pennsylvania, 215-349-8141. Thank you very much for your valuable participation in this research.

Sean Bouvrette Project Manager Women's Health Study University of Michigan

TOD	AY'S DATE	l			ID	
			INTERIM QUEST	ΠΟΝΝΑΙRE - A		
		GENE	TIC TEST	NG-SECT	ON 1	
1.		contributed a blo	od or tissue sample	to the GENETIC	FESTING portion of the	research
	project?		□ Yes □ N			B21.
2.	Has any n	nember of your fa the research proje	mily contributed a	blood or tissue sam	ple to the <u>GENETIC T</u>	<u>ESTING</u>
	portion or	the research proje	☐ Yes ☐ N	Io 🗌 I Don't K	Know	B22.
3.	Have vou	or any family men	mbers received noti	fication that genetic	results are available?	B23.
		There Has Been No Notification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible	
4.		received results of Yes	of genetic testing for o (Skip to Question	r breast or ovarian n 5)	cancer?	
	4a	. When did th	is occur?	(r	no/yr)	
	4b	What was th☐ Universit	ne source of this info y of Pennsylvania	ormation? ☐ Independent	Testing □Other:	
	4c	. What were t	he results? (Optiona	al)		
5.		Tamily member ro	eceived results of a o (Skip to Next Se	genetic testing for to ction) Don	oreast or ovarian cancer 't Know (Skip to Next	? Section)
	5a	. When did th	is occur?	(r	no/yr)	
	5b		ne source of this info y of Pennsylvania		Testing Other:	
	5c	. What were t	he results? (Option:	al)		
	5 d	able to figur	e out whether you a for breast cancer wi	are positive or nega	ive's results (i.e., Have tive for the gene that co?)	you been nveys

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagr				rongly Igree	
a.	If you don't have your health, you don't have anything.	1	2	3	. 4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	11	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	- 5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5_	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

))	1 11 111 3	lefinitely take t	he test <u>immedia</u>	tely when it be	ecomes available
	~ '11		he test, but I am		
					comes available
3) 4)	- 111		ne test, but not i		
i)	_		er I will take th		
))		probably not tal			
7)	w 111	lefinitely not ta			
	hay be at increas				
	Not At All Distressing				Very Distressing
	Distressing 1	2 o be given the	3	4 be tested for the	Distressing 5
low o	Distressing	o be given the	opportunity to b	be tested for th	Distressing 5
w (∶alt	Distressing 1 distressing it is the tered gene associated Not At All	o be given the	opportunity to b	be tested for th	Distressing 5 ne BRCA-1 gene Very
he al	Distressing 1 distressing it is the tered gene associated Mot At All Distressing	o be given the clated with incre	opportunity to based risk for bro	be tested for the east cancer?	Distressing 5 ne BRCA-1 gene Very Distressing

6.	How distressed would you be if you took the test and found that you did	not have
0.	the BRCA-1 gene?	

Not At All Distressed				Very Distressed
1	2	3	4	5

7. Overall, to what extent do you welcome the opportunity to be tested for the BRCA-1 gene?

B71.

B70.

Not At All				Very Much So
1	2	3	4	5

		Not A	t All		All Th	e Time
8.	How often do you worry about again developing breast cancer?	1	2	3	4	5
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5
10.	How often do you worry about having the altered gene carrying risk for breast cancer?	1	2	3	4	5
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5

B27.

B28.

B29.

B30.

12. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? (Please circle one)

B7.

Much Les Likely	S		M	uch More Likely
1	2	3	4	5

13.	When was the last time you had	I a mammography?	B32
	Ye	ar (-8) ☐ This question does not apply because	of surgery.
14.	How many times have you conpast six months?	ducted a breast self-examinations (BSE) in the	В33
	times	(-8) This question does not apply because of	f surgery.

15.	How	confident are	fident are you that you will perform breast self examination (BSE)								
	15a.	as freque	ntly as	needed?	(-8) 🗆 D	oes Not	Apply B	ecause of Surgery	B34a.		
		Not at All	2	3	4	5	6 V	Very Much So			
	15b.	as carefu	lly an	d compe	tently as	s needed Does N	l? Not Apply	y Because of Surgery	B34b.		
		Not at All	2	3	4	5	6	Very Much So 7			

For each of the following areas of your life, you will be asked to make <u>two</u> ratings. First, indicate how much these decisions have been affected by <u>the possibility that you have an increased risk for breast cancer</u> (based on your family history). Second, how much would these decisions be affected by <u>the results of genetic testing</u>?

1	2	3	4	5
Not at all affect	eted			Very much affected

					ed by l		Would be affected by the results of genetic testing					
16.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B: B:
17.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B. B.
18.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B: B:
19.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B: B:
20.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B: B:
21.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B. B.

22.	Answer the following question only if you have (biological) daughters.
	☐ Does Not Apply (Skip to Next Section, Life Events)

					by being Would be affected by the st cancer results of genetic testing						
a. Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42: B421

B41.

LIFE EVENTS SECTION

a.	You retired, were fired, or laid off from work.	g.	A close family member was seriously ill or injured.
b.	You were unemployed and looking for work.	h.	You had a marital separation or divorce.
c.	Your spouse retired, was fired, or laid off from work.	i.	You had serious troubles with relative or close friends.
d	Your spouse was unemployed and looking for work.	j.	Your spouse had troubles or difficulties with relatives or close
e.	You had problems with the police or	_	friends.
	court.	k.	A close family member died.
f.	You got into serious financial	1.	A close friend or relative died.
••	difficulties.	m.	You were seriously ill or injured.

MARRIAGE SECTION

The following questions apply to persons who are <u>married or living with</u> a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner \Box

H3.

H4.

H6.

H7.

H12.

H15.

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree
1.	Religious matters	6	5	4	3	2	1
2.	Demonstration of affection	6	5	4	3	2	1
3.	Sex relations	6	5	4	3	2	1
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1
5.	Making major decisions	6	5	4	3	2	1
6.	Career decisions	6	5	4	3	2	1

								ı
		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	Н16.
8.	Do you ever regret that you married (or are living together)?	1	2	3	4	5	6	H20.
9.	How often do you and your husband/partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your husband/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

	All of	Most of	Some of	Very few	None of
	Them	Them	Them	of Them	Them
11. Do you and your husband/partner engage in outside interests together?	5	4	3	2	1

H24.

How often would you say the following events occur between you and your husband/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

15. Considering only the positive feelings you have toward your husband/partner, and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not A Posi									emely sitive
1	2	3	4	5	6	7	8	9	10

16. Considering only the negative feelings you have toward your husband/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your husband's involvement in your health care.

		Never				Very Often	
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2_	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	H35b.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	Н35с.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4_	5	H35d.

18.	Has your husband/partner attended individual, family or group sessions to become informed about your risk for breast cancer and what can be done?
-----	---

H36.

(1) Yes
$$\Box$$
 (5) No \Box

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer.

Н37.

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it?

Н38.

To what extent are you satisfied with your husband/partner's involvement in your health care?

Н39.

MOOD SECTION

Ι.	Have you ever in your lifetime had two weeks or more when hearly every day you lest blue, or depressed <u>or</u> in which you lost all interest in things like work or hobbies or things usually liked to do for fun?								
		(1) □ Yes	(5) ☐ No (Skip to Question 2)	I14					
	1a.	If there was s	such a two-week period, did your work or relationships suffer?	I14a.					
		(1) □ Yes	(5) □ No						
	1b.	If there was supposed the supposed in the supp	uch a two-week period, did you get counseling or y?	I14b.					
		(1) □ Yes	(5) □ No						
	1c.	If there was s for this condit	such a two-week period, did you get medication tion?	I14c.					
		(1) □ Yes	(5) □ No						
2.	felt sag	d. blue, or depr	s, have you had two weeks or more when nearly every day you ressed or in which you lost all interest in things like work or a usually liked to do for fun?	I12.					
		(1) ☐ Yes	(5) ☐ No (Skip to Question 3)						
	2a.	If there was s your work or	such a two-week period in the past 6 months, did relationships suffer?	I12a.					
		(1) ☐ Yes	(5) □ No						
	2b.	If there was s counseling or	such a two-week period in the past 6 months, did you get psychotherapy?	I12b.					
		(1) ☐ Yes	(5) □ No						
	2c.	If there was s medication fo	such a two-week period in the past 6 months, did you get or this condition?	I12c.					
		(1) ☐ Yes	(5) □ No						
3.	Are yo	ou currently re otional problem	eceiving counseling, psychotherapy or medication for depression as?	I13.					
		(1) \(\subseteq \text{Yes}	(5) □ No						

STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		Not at all	<u>A little</u>	Quite a bit	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	К3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	К9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	11	2	3	4	K18.
19.	Feeling lonely	11	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	11	2	3	4	K24.
25.	Feelings of worthlessness	11	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
1.	Having compassion for others.	1	2	3	4	5	6	L61.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says, how much or how frequently. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4
c.	I've been saying to myself "this isn't possible."	1	2	3	4
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
e.	I've been getting emotional support from others.	1	2	. 3	4
f.	I've been giving up trying to deal with it.	1	2	3	4
g.	I've been taking action to try to make the situation better.	1	2	3	4
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
1.	I've been trying to come up with a strategy about what to do.	1	2	3	4
m.	I've been getting comfort and understanding from someone.	1	2	3	4

14

L7a.

L7b.

L7c.

L7d.

L7e.

L7f.

L7g.

L7h.

L7i.

L7j.

L7k.

L71.

L7m

		I haven't been doing this at all 1	I've been doing this a little bit	I've been doing this some 3	I've been doing this a lot 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	
0.	I've been accepting the possibility that I might have the gene.	1	2	3	4	
p.	I've been expressing my negative feelings.	1	2	3	4	
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4	
s.	I've been thinking hard about what steps to take.	1	2	3	4	
t.	I've been praying or meditating.	1	2	3	4	
u.	I've been making fun of the situation.	1	2	3	4	

The following items are to be answered only by those women who are <u>married or living with a partner</u>.
 (-8) □ Not married or living with a partner
 (Skip to Last Section on page 15, Background Data)

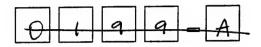
	I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a. I've been denying or hiding my anger around my husband/partner.	1	2	3	4
b. I've been denying or hiding my worries around my husband/partner.	1	2	3	4
c. I've been avoiding talking about my problems around my husband/partner.	1	2	3	4
d. I've acted more positive around my husband/partner than I feel.	1	2	3	4 .

BACKGROUND DATA

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

. Relig	gion:	Catholic Jewish Muslim	(1)	Protestant Buddhist Other None	(4) □ (5) □ (6) □ (7) □	A3
1a.	How often do yo (1) □ Less Often Th		(5))	A Month or More	A3a
1b.	How important a	re religious a	and spiritual	beliefs in your l	ife?	A3b
	Not at All	2	3	Ve 4	ry Important 5	

Once Again, We thank you for all of your valued participation in this study.







WOMEN'S HEALTH STUDY

Interim Questionnaire

As you may already know, there are two components to this breast cancer research--a study of the biology of genetics, which is now located at the University of Pennsylvania (previously it was at the University of Michigan) and a study of the personal and social aspects of genetic testing which is located at the University of Michigan. This questionnaire is part of the study of personal and social aspects. Some of these questions will be familiar. We are asking them again to learn more about how feelings and attitudes change over time.

If you have any questions about this questionnaire or research, please feel free to call me at 313-998-6560. For questions about the genetic testing component, you may call Kathleen Calzone at the University of Pennsylvania, 215-349-8141. Thank you very much for your valuable participation in this research.

Sean Bouvrette Project Manager Women's Health Study University of Michigan

ID	199-A
\mathbf{ID}	W 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1

			INTERIM QUES	TIONNAIRE - U		
		GENI	ETIC TEST	ING-SECT	ION 1	
1.	Have yo project?	ou contributed a bl	ood or tissue sample	to the GENETIC	<u>FESTING</u> portion of the	e research
	project.		□ Yes □ N	1 0		B21.
2.		member of your		blood or tissue san	aple to the <u>GENETIC T</u>	<u>ESTING</u>
	portion	or the research pre	☐ Yes ☐ N	No 🗆 I Don't F	Know	B22.
3.	Have vo	ou or any family m	embers received not	ification that genetic	c results are available?	B23.
	114,0 90	There Has Been No Notification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible	
4.		□ Yes □	of genetic testing for No (Skip to Question this occur?	n 5)	cancer?	
	4		the source of this inf ity of Pennsylvania		Γesting □Other:	
	4	4c. What were	the results? (Option	al)		
5.	-		received results of a No (Skip to Next Se	ction) \square Dor	preast or ovarian cancer o't Know (Skip to Next	:? : Section)
	5	Sa. When did	this occur?	(r	no/yr)	
	4		the source of this infity of Pennsylvania		Γesting □Other:	
	5	5c. What were	the results? (Option	al)		
		able to figu higher risk	fer your genetic resure out whether you a for breast cancer wi	are positive or nega	ive's results (i.e., Have tive for the gene that co?)	you been nveys

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

			Strongly Disagree			Strongly Agree		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.	
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.	
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.	
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.	
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.	
f.	It's easy for me to relax.	1	2	3	4	5	E2.	
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.	
h.	I always look on the bright side of things.	1	2	3	4	5	E4.	
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.	
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.	
k.	It's important for me to keep busy.	1	2	3	4	5	E7.	
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.	
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.	
n.	I don't get upset too easily.	1	2	3	4	5	E10.	
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.	
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.	

GENETIC TESTING-SECTION 2

risk you	edical test may soo for developing a fo consider taking thi ase check one	orm of breast a is genetic test? response).	nd ovarian cand	cer that runs in I	ammes. Would	B 1
(1)					omes available.	
(2)			ne test, but I am			
(3)	I will p	robably take th	e test immediate	ely when it beco	omes available.	
(4)	I will p	robably take th	e test, but not it	mmediately.		
(5)	I am <u>ur</u>	ndecided wheth	er I will take the	e test		
(6)		robably not tak	te the test.			
(7)		efinitely not tal	ke the test.			
On t you	he following scale may be at increase	e, indicate how ed risk for breas	distressing it is st cancer because	for you to kno se of your famil	w that y history?	В
	Distressing				Distressing	
	1	2	3	4	5	
How the a	Not At All Distressing	o be given the cated with incre	opportunity to based risk for bro	e tested for the east cancer?	Very Distressing	В
	1	2	3	4	5	
How	v distressed do you e (before you recei	expect to be ve results)?	when you actua	lly get tested fo	or the BRCA-1	В
	Not At All Distressed				Very Distressed	
	1	2	3	4	5	
Hov BRO	v distressed would CA-1 gene?	l you be if you	took the test an	d found that yo	ou had the	В
	Not At All Distressed				Very Distressed	

6.	How distressed would you be if you took the test and found that you the BRCA-1 gene?	did not have
	uic Brest gone.	

Not At All Distressed

Very	
Distressed	

1	2	3	4	5	
	. 1	a the ennertu	nity to be tested	for the BRCA-	1

B71.

B70.

7.	Overall, to what extent do you welcome the opportunity to be tested for	the BRCA-1
	gene?	

Not At All				Very Much So
1	2	3	4	5

		Not At All			All The Time		
8.	How often do you worry about developing breast cancer?	1	2	3	4	5	
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	
10.	How often do you worry about having the altered gene carrying risk for breast cancer?	1	2	3	4	5	
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	

B27.

B28.

B29.

В30.

12.	When was the last time you had a mammography? (-8) MonthYear	В32.
13.	How many times have you conducted a breast self-examinations (BSE) in the past six months?	взз.
	times (-8) This question does not apply because of surgery.	

14.	How confident are you that you will perform breast self examination (BSE)									
	14a	-as f requent	ly as no	eeded?	(-8)	Does No	ot Apply 1	Because of Su	rgery	B34a.
		Not at All	2	3	4	5	6 V	Yery Much So		
	14b.				etently	as neede	ed?	oly Because o		B34b.
		Not at All	2	3	4	5	6	Very Much So		

For each of the following areas of your life, you will be asked to make <u>two</u> ratings. First, indicate how much these decisions have been affected by <u>the possibility that you have an increased risk for breast cancer</u> (based on your family history). Second, how much would these decisions be affected by <u>the results of genetic testing</u>?

				_
1	2	3	4	5
Not at all affected	<u> </u>			Very much affected

			been risk f				Would be affected by the results of genetic testing					
15.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
16.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
17.	Decisions about which steps to take to prevent the occurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
18.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38a B38b
19.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
20.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

21. Answer the following question only if you have (biological) daughters.

☐ Does Not Apply
(Skip to Question 22)

B41.

								0.0		.1	1
	Have	been	affecte	ed by	<u>being</u>	<u>Wo</u>	<u>uld_be</u>	affect	ed by	<u>tne</u>	1
				reast c		res	ults of	f genet	ic test	ing	
a. Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42

Do you feel you have enough information about breast cancer to make any decisions that might be necessary?

Not At All						Very Much
1	2	3	4	5	6	7

23. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer?

Not At All						Very Much
1	2	3	4	5	6	7

Do you feel you are adequately informed about what you could do to reduce your risk of breast cancer if you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	. 5	6	7

B46.

B45.

B43.

B44.

26. Do you feel you are adequately informed about what it would mean for your children if you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B47.

27. How confident are you that you:

a. Will make the best decision in deciding whether to be tested for BRCA1, the altered gene associated with risk of breast cancer?

Not At All						Very Much
1	2	3	4	5	6	7

B48a.

b. Would cope effectively with a finding that you had the altered BRCA1 gene?

Not At All		-				Very Much
1	2	3	4	5	6	7

B48b.

c. Would make the best decision concerning your options if you were found to have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48c.

d. Would be able to follow through and cope effectively over the long haul if you were found to have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1.	Is ther	e anyone in your l	ife with who	m you can s	share y	our mos	t private feelings	C21.
	witho	ut holding back?	(1) ☐ Yes	(5) 🗆 No				
2.	If mar holdin	ried, can you share g back?	e your most p	orivate feeli (5) □ No		th your l	nusband without	C21a.
3.	If mar	ried, is there anyonost private feeling	ne besides yo gs without ho (1) □Yes	our husband lding back (5) No	!	whom yo	ou can share	C21b.
1.	Have :	any of the followinck All That Ap	IFE E				x months?	D1(a-m)
a.		You retired, were from work.	e fired, or lai	d off	g.		A close family member vill or injured.	vas seriously
b.		You were unemp	oloyed and lo	oking for	h.		You had a marital separate divorce.	tion or
c.		work. Your spouse retiliaid off from wo	red, was fire	d, or	i.		You had serious troubles or close friends.	with relatives
d		Your spouse was looking for work	s unemploye	d and	j.		Your spouse had troubles difficulties with relatives	s or or close
e.		You had problem court.	ns with the p	olice or	k.		friends. A close family member d	
f.		You got into seri difficulties.	ous financial		l. m.		A close friend or relative You were seriously ill or	

MARRIAGE SECTION

The following questions apply to persons who are <u>married or living with</u> a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner \Box E-a.

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree
1.	Religious matters	6	5	4	3	2	1
2.	Demonstration of affection	6	5	4	3	2	1
3.	Sex relations	6	5	4	.3	2	1
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1
5.	Making major decisions	6	5	4	3	2	1
6.	Career decisions	6	5	4	3	2	1

		All of the time	Most of the time	More often than most	Occa- sionally	Rarely	Never	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	Н16.
8.	Do you ever regret that you married (or are living together)?	1	2	3	4	5	6	H20.
9.	How often do you and your husband/partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your husband/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

H3.

H4.

H6.

H7.

H12.

H15.

	All of	Most of	Some of	Very few	None of
	Them	Them	Them	of Them	Them
11. Do you and your husband/partner engage in outside interests together?	5	4	3	2	1

H24.

How often would you say the following events occur between you and your husband/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

Considering only the positive feelings you have toward your husband/partner, 15. and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not A Posi									emely sitive
1	2	3	4	5	6	7	8	9	10

H34.

and ignoring the positive ones, please rate how negative these feelings are: Extremely Not At All Negative Negative 8 10 6 4 5 3 2

Considering only the negative feelings you have toward your husband/partner,

16.

1

17. The following questions concern your husband's involvement in your health care.

		Never				Very Often	
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H352
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	Н351
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	Н350
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3_	4	5	Н35с

18.	Has your husband informed about yo	/partner our risk f	attended for breast Yes	cancer as	al, family nd what of S	can be do	p sessions to become one?	Н36.
19.	How much contact concerning your r	et has you	ur husban reast can	nd/partner cer.	had wit	th medica	al personnel	Н37.
	Very Little or None 1		3	4	5	6	A lot	
20.	Do you feel your cancer and what c	husband an be do	/partner is ne about	s adequat it?	ely infor		cerning your risk for breas	t H38.
	Not at All 1	2	3	4	5	6	Very Much 7	
21.	To what extent ar	e you sat	tisfied wi	th your h	usband/j	partner's	involvement in your	Н39.

Not at All

Very Much 7

MOOD SECTION

1.	blue, c	or depressed or	our lifetime had two weeks or more when nearly every day you fe in which you lost all interest in things like work or hobbies or thing	lt sad, s you
	usually	y liked to do for	r fun?	I14
		¹ □ Yes	5 ☐ No (Skip to Question 2)	
	1a.		such a two-week period, did your work or relationships suffer? 5	I14a.
		☐ Yes	□ No	
	1b.	If there was supposed the psychotherapy	5	I14b.
		☐ Yes	□ No	
	1c.	If there was s for this condit	5	I14c.
		☐ Yes	□ No	
2.	felt sa	d blue, or depr	s, have you had two weeks or more when nearly every day you ressed or in which you lost all interest in things like work or a usually liked to do for fun? No (Skip to Question 3)	I12.
	2a.	If there was s your work or 1 \(\text{Yes} \)	such a two-week period in the past 6 months, did relationships suffer? 5 No	I12a.
	2b.	If there was s counseling or 1	such a two-week period in the past 6 months, did you get psychotherapy? 5 No	I12b.
	2c.	If there was s medication fo 1	such a two-week period in the past 6 months, did you get or this condition? 5 No	I12c.
3.	Are yo	ou currently reptional problem	eceiving counseling, psychotherapy or medication for depression as? 5 No	I13.

STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		Not at all	<u>A little</u>	Quite a bit	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	К3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
.20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
1.	Having compassion for others.	1	2	3	4	5	6	L61.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says, how much or how frequently. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a L7b
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L75
c.	I've been saying to myself "this isn't possible."	1	2	3	4	
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d
e.	I've been getting emotional support from others.	1	2	3	4	L7e
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4	L7h
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k
1.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L71
m.	· · · · · · · · · · · · · · · · · ·	1	2	3	4	L7n

	I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
n. I've been giving up the attempt to cope.	1	2	3	4
o. I've been accepting the possibility that I might have the gene.	1	2	3	4
p. I've been expressing my negative feelings.	1	2	3	4
q. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r. I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s. I've been thinking hard about what steps to take.	1	2	3	4
t. I've been praying or meditating.	1	2	3	4
u. I've been making fun of the situation.	11	2	3	4

3. The following items are to be answered only by those women who are <u>married or living with a partner</u>.

□ Not married or living with a partner

(Skip to Last Section on page 15, Background Data)

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	_
a.	I've been denying or hiding my anger around my husband/partner.	. 1	2	3	4	L L
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4	L
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4	L
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4	

BACKGROUND DATA

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1.	Religion	:	Catholic Jewish Muslim	(1)	Protestant Buddhist Other None	(4) ☐ (5) ☐ (6) ☐ (7) ☐	A3.
	1a.	How often do yo (1) Less Often Th		(5)	A Month or More	A3a.
	1b.	How important a	are religious a	and spiritual	beliefs in your li	fe?	A3b.
		Not at All	2	3	Ver 4	ry Important 5	

Once Again, We thank you for all of your valued participation in this study.





WOMEN'S HEALTH STUDY

Spouse/Partner Questionnaire

Today's Date	
--------------	--

U-ID		

SPOP

BACKGROUND DATA SECTION

1.	Date of Birth	Month	Day _	Year		A1.
2.	Ethnic Background:	White Hispanic Native American	□ 1 □ 2 □ 3	Black Asian Other	□ 4□ 5□ 6	A2.
3.	Religion:	Catholic Jewish Muslim	☐ 1 ☐ 2 ☐ 3	Protestant Buddhist Other None	□ 4□ 5□ 6□ 7	A3.
		you attend religious se in Once a Month		Few Times A Mor	nth or More	A3a.
	3b. How importan Not at All	t are religious and spir	itual belief 4	Very Imp	ortant	A3b.
4.	Are you currently work	ng for pay outside the	home?	Yes □ 1 No	⊃ □ 5	A7.
5.	If <u>yes</u> , about how many	hours per week are ye	ou working	g for pay?		A8.
	Less than 10 1 (1)	0-20 21-30 (2) (3)		31-40 41 (4)	or more (5)	
6.	What is the highest level 1 □ Less than 9th grade 2 □ Dropped out of high 3 □ Completed high scho 4 □ Some college	school	5 □ C 6 □ S	ompleted college ome graduate or	e professional training te or professional trainir	A9.
The Plea	following two questions se check the appropriate b	are optional, but we ox. (Check one)	e hope tha	t you will provi	de this information.	
7.	What is your household's	total income? (Check	k one)			A10.
	(1) Less than \$10,00 (2) \$10,000 to \$19,0 (3) \$20,000 to \$29,0	999 (5) 🗆 \$40,0	000 to \$39 000 to \$49 000 to \$59),999 (8) □	\$60,000 to \$69,999 Greater than \$69,999	
8.	How many people (adults	and children) does this	s income si	upport?	_	A11.

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagn				rongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	Nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	11	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1_	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3_	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

HEALTH SECTION

The following questions concern your wife/partner's risk of developing breast cancer and of her having the altered gene which has been found to be associated with increased risk for breast cancer. As you may know, breast cancer runs in certain families. In some of these families, persons who develop cancer have an altered version of a gene, BRCA1. Some family members will inherit the gene and others will not.

		Not At All				All The Time
1.	How often do you worry about your wife/partner developing breast cancer?	1	2	3	4	5
2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5
3.	How often do you worry about your wife/partner having the altered gene associated with risk for breast cancer?	1	2	3	4	5
4.	To what extent do worries about your wife/partner having this altered gene interfere with your every day life?	1	2	3	4	5
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5

6. How likely do you think your wife/partner is to develop breast cancer in the near future?

(Please circle one).

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

7. Overall, what do you believe your wife/partner's risk is of developing breast cancer at some point in her lifetime?

0%

10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B10.

B49.

8. Overall, what do you believe your wife/partner's risk is of developing some other cancer **unrelated** to breast cancer **at some point in her lifetime?**B14.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

9. How often does your wife/partner express concern and seek support from you about the risk of breast cancer to herself and women in her family?

NeverRarelySometimesOften1234

How much of a burden is this on you? 10.

Not At All	A Little	Somewhat	A Great Deal		
1	2	3	4		

How often do you discuss genetic testing for breast cancer with your wife/partner? 11.

Never	Rarely	Sometimes	Often		
1	2	3	4		

When you have these discussions, who generally initiates them? 12.

You	Your Wife/partner	Equally
1	2	3

How satisfied are you with these discussions? 13.

Not At All A Little		Somewhat	A Great Deal	
1	2	3	4	

How often do you and your wife/partner get into a disagreement or conflict over the issue of 14. her getting genetic testing for the risk of breast cancer?

Never	Rarely	Sometimes	Often		
1	2	3	4		

Do you think it is beneficial to have genetic testing for risk of breast cancer available to women? B55. 15.

Not At All A Little		Somewhat	A Great Deal		
1	2	3	4		

Do you want your wife/partner to get genetic testing for risk of breast cancer? 16.

Not At All	A Little	Somewhat	A Great Deal		
1	2	3	4		

4

B50.

B51.

B52.

B54.

B53.

B56.

17.	Overall, how much wife/partner's dec	h do you want y ision whether	your opinion to to be tested for	o be taken into or the breast c	account in your cancer gene?	B57.
		Not At All	A Little	Somewhat	t A Great Deal	
		1	2	3	4	
18.	Overall, how much wife/partner's dec	h do you want y isions about v	your opinion to what to do abo	be taken into out her risk f	account in your for breast cancer	? B58.
		Not At All	A Little	Somewhat	A Great Deal	
		1	2	3	4	
19.	Overall, how imposor the altered gen	e carrying susce	eptibility to bre	ast cancer?		to be tested B59.
		Not At All	A Little	Somewhat	A Great Deal	
		1	2	3	4	
	Do you believe your How confident are you		(1) \square Yes	increases the r	isk of breast canc	eer? B60.
170.	Not At Al				Very	7
	Confident				Confident	
	1	2 3	4	5	6 7	В61.
20.	Have you attended wife/partner's risk				ome informed abo	out your B62.
		(1)	\square Yes (5)	□No		
21.	How much contact	have you had v	with medical pe	ersonnel conce	rning her risk of	cancer? B63.
	Very Little 1	2 3	4 5	6	A Lot 7	
			5			

22.	Overall, do you feel you are adequately informed concerning your wife/partner's risk for cancer and what can be done about it?							ng your wife/partner's risk for	B43a.
		Not at All	2	3	4	5	6	Very Much 7	
23.	Do yo	ou feel you ar testing for	e adequa	tely infor	rmed abover?	out the b	enefits	and drawbacks of genetic	B44.
		Not at All	2	3	4	5	6	Very Much 7	
24.	Do yo	ou feel you are reduce her	e adequa risk of b	tely infor	rmed abover if she	out what had the	your v	vife/partner could do personally to I BRCA1 gene?	B45.
		Not at All	2	3	4	5	6	Very Much 7	
25.	Do yo	ou feel you are options ava	e adequa ilable to	tely infor women v	med abo	out the be the alte	enefits ered BR	and drawbacks of CA1 gene?	B46.
		Not at All	2	3	4	5	6	Very Much 7	
26.	Do yo	ou feel you are wife/partne	e adequa er had th	tely infor e altered	med abo	1 gene?	C	ld mean for your children if your Check here if you do not have ch	B47. nildren.
		Not at All	2	3	4	5	-8)	Very Much 7	
27.	How	confident are	you that	your wif	e/partne				
	27a.	Will make t associated v					be test	ed for BRCA1, the altered gene	B48a.
		Not at All	2	3	4	5	6	Very Much 7	
	27b.	Would cope	effectiv	ely with	the findi	ng that s	he had	the altered BRCA1 gene?	B48b.
		Not at All	2	3	4	5	6	Very Much 7	
	27c.	Would mak have the alte				ning her	option	s if she were found to	B48c.
		Not at All	2	3	4	5	6	Very Much 7	
	27d.	Would be all long haul if	ble to fol she were	low throus	agh with have th	her dec e alterec	isions a	and cope effectively over the A1 gene?	B48d.
		Not at All	2	3	4	5	6	Very Much	

Please indicate the extent to which you agree or disagree with the following statements using the 1 (strongly disagree) to 5 (strongly agree) scale. Please try to provide your opinion for all of these questions. However, if you feel you simply do not know enough to have an opinion, check the "I don't know" box.

		Strong Disag				trongly Agree	I Don't Know	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	В20с.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.
g.	If a woman were found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5	9	B20m.
h.	Once a woman has had effective treatment for breast cancer, she will not get it again.	1	2	3	4	5	9	B20n.
i.	A mastectomy totally eliminates a woman's risk for breast cancer.	1	2	3	4	5	9	B20o.
j.	All women who have the altered version of the BRCA1 gene will get breast cancer.	1	2	3	4	5	9	B20p.
k.	Most of the breast cancer in the United States is due to altered versions of the BRCA1 gene.	1	2	3	4	5	9	B20q.
1.	The next decade is going to bring major advances in the detection and treatment of breast cancer.	1	2	3	4	5	9	B20r.
m.	Over the next decade, medical break-through's are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9	B20s.

29. If your wife/partner were to take the test and find that she <u>did not</u> have the altered version of the BRCA1 gene which is associated with high risk for breast cancer, what would you expect your reactions to be?

			Strongly Disagree			rongly Agree	
a.	I would feel wonderful.	1	2	3	4	5	B18a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B18b.
c.	I would feel relieved.	1	2	3	4	5	B18c.
d.	I would not believe the results.	1	2	3	4	5	B18d.
e.	I would fall apart emotionally.	1	2	3	4	5	B18e.
f.	I would feel guilty.	1	2	3	4	5	B18f.
g.	I would still feel anxious.	1	2	3	4	5	B18g.
h.	I would feel angry.	1	2	3	4	5	B18h.
i.	I would feel prepared for the future.	1	2	3	4	5	B18i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B18j.
k.	I would not feel very differently.	1	2	3	4	5	B18k.

30. If your wife/partner were to take the test and find out that she <u>had</u> the altered version of the BRCA1 gene for breast cancer, what would you expect your reactions to be?

		Strong Disag				trongly Agree	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B19a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	В19Ъ.
c.	I would not believe the results.	1	2	3	4	5	В19с.
d.	I would feel guilty.	1	2	3	4	5	B19d.
e.	I would feel depressed.	1	2	3	4	5	B19e.
f.	I would feel worried about the future.	1	2	3	4	5	B19f.
g	I would fall apart emotionally.	1	2	3	4	5	B19g.
h.	I would feel anxious.	1	2	3	4	5	B19h.
i.	I would feel angry.	1	2	3	4	5	B19i.
j.	I would not feel very differently.	1	2	3	4	5	B19j.
k.	I would want my daughters to be tested as soon as possible.	1	2	3	4	5	B19k.

31. The following questions concern your involvement in your wife/partner's health care:

		Not at All				Very Often
a.	To what extent do you go with your wife/partner to her appointments with doctors?	1	2	3	4	5
b.	To what extent do you talk with your wife/partner's doctor or other medical personnel about her risk of cancer?	1	2	3	4	5
c.	To what extent do you keep track of what your wife/partner needs to do about her risk of cancer?	1	2	3	4	5
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5

H35a.

Н35Ь.

Н35с.

H35d.

- 32. If my wife/partner were tested and found to have the altered BRCA1 gene carrying increased risk of breast cancer, I would want her to manage her risk by relying on:
 - a. Being extra careful about breast self-examination and regular medical examinations.

B64a.

Not at All						Very Much So
1	2	3	4	5	6	7

b. Getting preventive surgery.

B64b.

Not at All						Very Much So
1	2	3	4	5	6	7

33. I do not believe it would be my place to tell my wife/partner my opinion about what she should do about her risk of breast cancer.

B65.

Strongly Disagree						Strongly Agree
1	2	3	4	5	6	7

RELATIONSHIPS

1.	Is there anyone in your life with whom you without holding back?	ı can share your	most private feelings	C21.
	$(1) \square \text{ Yes } (5) \square \text{ No}$			
2.	Can you share your most private feelings v	vith your wife/pa	artner without holding back?	C21a.
	(1) \square Yes (5) \square No			
3.	Is there anyone besides your wife/partner without holding back?	vith whom you o	can share your most private feelings	C21b.
	(1) \square Yes (5) \square No			
4.	Have any of the events listed below happen (Check All That Apply)	ned to you in <u>the</u>	e past six months?	D1 (a-m
a.	You retired or were fired or laid off from work.	g.	 A close family member was seriously ill or injured. 	
b.	You were unemployed and looking for work.	h.	 You had a marital separation o divorce. 	r
c.	☐ Your spouse retired or was fired or laid off from work.	i.	You had serious troubles with relatives or close friends.	
d	Your spouse was unemployed and looking for work.	j.	 Your spouse had troubles with relatives or close 	
e.	You had problems with the police or court.	k.	friends. A close family member died.	
f.	☐ You got into serious financial difficulties.	1. m.	A close friend or relative died.You were seriously ill or injure	ed.

MARRIAGE SECTION

Most people have disagreements in their relationships. Please indicate, using check marks the extent of agreement or disagreement experienced between you and your wife/partner on the following issues **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree	
1.	Handling family finances	1	2	3	4	5	6	Н1.
2.	Matters of recreation	1	2	3	4	5	6	Н2.
3.	Religious matters	1	2	3	4	5	6	Н3.
4.	Demonstration of affection	1	2	3	4	5	6	Н4.
5.	Friends	1	2	3	4	5	6	Н5.
6.	Sex relations	1	2	3	4	5	6	Н6.
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	Н7.
8.	Philosophy of life	1	2	3	4	5	6	Н8.
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	Н9.
10.	Aims, goals, and things believed important	1	2	3	4	5	6	H10.
11.	Amount of time spent together	1	2	3	4	5	6	H11.
12.		1	2	3	4	5	6	H12.
	Household tasks	1	2	3	4	5	6	Н13.
14.		1	2	3	4	5	6	Н14.
15.	Career decisions	1	2	3	4	5	6	H15.

		All of the Time	Most of the Time	More Often than Most	Occa- sionally	Rarely	Never	
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	Н16.
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5	6	H17.
18.	In general, how often do you think that things between you and your wife/partner are going well?	1	2	3	4	5	6	H18.
19.	Do you confide in your wife/partner?	1	2	3	4	5	6	H19.
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6	H21.
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6	Н22.

	Every Day	Almost Every Day	Occa- sionally	Rarely	Never	
you kiss your e/partner?	1	2	3	4	5	Н23.

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them	
24.	Do you and your wife/partner engage in outside interests together?	1	2	3	4	5	Н24.

How often would you say the following events occur between you and your wife/partner? About Less than About Once a More once a twice a twice a dav Often Never month month week Have a stimulating exchange 3 4 5 6 2 1 25. H25. of ideas 3 1 2 4 5 6 26. Laugh together H26. 2 3 4 5 6 1 27. Calmly discuss something H27. 1 2 3 4 5 6 28. Work together on a project H28. These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. (Check ves or no). 29. (1) \(\sum \) Yes (5) No H29. Being too tired for sex. (5) \(\sup \) No H30. 30. Not showing love. (1) **Yes** The following scale represents different degrees of happiness in your relationship. The 31. middle point "happy" represents the degree of happiness of most relationships. Please circle the number which best describes the degree of happiness, all things considered, of vour relationship. H31. A Little Very Extremely Extremely Fairly Perfect Unhappy Unhappy Unhappy Happy Happy Happy 7 4 5 6 1 2 3 Please check one of the following statements to best describe how you feel H32. 32. about the future of your relationship. (1). I want desperately for my relationship to succeed, and would go to almost any length to see that it does. (2).___I want very much for my relationship to succeed, and will do all I can to see that it does. (3).___I want very much for my relationship to succeed, and will do my fair share to see that it does. It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed. It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

My relationship can never succeed, and there is no more that I

can do to keep the relationship going.

33. Considering only the positive feelings you have toward your wife/partner, and ignoring the negative ones, please rate how positive these feelings are:

Н33.

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

Considering only the negative feelings you have toward your wife/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Nega									emely gative
1	2	3	4	5	6	7	8	9	10

CURRENT FAMILY SECTION

Please indicate the extent to which each of the following items describes your current family (your household).

Please indicate the extent to which each of the research		Strongly Disagree			Strongly Agree		
1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	М1.
2.	In times of crisis we can turn to each other for support.	1	2	3	4	5	М2.
3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	М3.
4.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
5.	We avoid discussing our fears and concerns.	1	2	3	4	5	М5.
6.	We can express feelings to each other.	1	2	3	4	5	М6.
7.	There are lots of bad feelings in the family.	1	2	3	4	5	М7.
8.	We feel accepted for who we are.	1	2	3	4	5	М8.
9.	Making decisions is a problem for our family.	1	2	3	4	5	М9.
10.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
11.	We don't get along well together.	1	2	3	4	5	M11.
12.	We confide in each other.	1	2	3	4	5	M12.

YOUR HEALTH AND MOOD SECTION

1.	In gen	eral, would	you say yo	our health is:				11.
	(1)	Excellent	(2) 🗆 Ve	ery Good	(3) ☐ Good	(4) 🗆 Fair	(5)	
2.	vou fe	It sad, blue,	or depress	had two week led <u>or</u> in which ally liked to de	ks or more when near n you lost all interest it o for fun?	ly every day n things like work		I14.
		(1)	□ Yes	(5) 🗆 No (Sk	kip to Question 3)			
	2a.	If there was	s such a tv	wo-week perio	od, did your work or re	elationships		I14a.
		(1)	☐ Yes	(5) 🗆 N o				
	2b.	If there was		vo-week perio	d, did you get counse	ling or		I14b.
		(1)	□ Yes	(5) 🗆 No				
	2c.	If there we condition?	as such a t	wo-week perio	od, did you get medica	ation for this		I14c.
		(1)	□ Yes	(5) 🗆 N o				
3.	vou fe	lt sad, blue,	or depress	you had two ed <u>or</u> in which ally liked to de	weeks or more when you lost all interest i o for fun?	nearly every day n things like work		I12.
		(1)	□ Yes	(5) 🗆 No (Sk	ip to Question 4)			
	3a.	If there wa	as such a t ships suffe	wo-week peri r?	iod (in the past 6 m	onths), did your work	Σ.	I12a.
		(1)	□ Yes	(5) 🗆 No				
	3b.		I12b.					
		(1)	☐ Yes	(5) 🗆 N o				
	3c.	If there wa medication	as such a to for this pr	wo-week peri oblem?	iod, (in the past 6 m	onths) did you get		I12c.
		(1)	□ Yes	(5) 🗆 N o				
4.	Are yo	ou currently ssion or emo	y receiving tional prob	g counseling, polems?	osychotherapy, or med	lication for		I13.
		(1)	□ Yes	(5) □ N o				

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		1 Not at all	2 A little	3 Ouite a bit	4 Extremely	
1.	Suddenly scared for no reason	1	2	3	4	,
2.	Feeling fearful	1	2	3	4	j
3.	Faintness, dizziness, or weakness	1	2	3	4]
4.	Nervousness or shakiness inside	1	2	3	4]
5.	Heart pounding or racing	1	2	3	4	
6.	Trembling	1	2	3	4	
7.	Feeling tense or keyed up	1	2	3	4	
8.	Headaches	1	2	3	4	
9.	Spells of terror or panic	1	2	3	4	
	Feeling restless, can't sit still	1	2	3	4	K
	Feeling low in energyslowed down	1	2	3	4	K
12.	Blaming yourself for things	1	2	3	4	K
13.	Crying easily	1	2	3	4	K
14.	Loss of sexual interest or pleasure	1	2	3	4	K
15.	Poor appetite	1	2	3	4	K
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K
17.	Feeling hopeless about the future	1	2	3	4	K
18.	Feeling blue	11	2	3	4	K
19.	Feeling lonely	1	2	3	4	K
20.	Feeling trapped or caught	1 .	2	. 3	4	K
21.	Worrying too much about things	1	2	3	4	K
22.	Feeling no interest in things	1	2	3	4	K
23.	Thoughts of ending your life	1	2	3	4	K
24.	Feeling everything is an effort	1	2	3	4	K
25.	Feelings of worthlessness	1	2	3	4	K

COPING SECTION

1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L1_1
b.	I would take a tranquilizer or have a drink before going.	1	5	L1_2
c.	I would try to think about pleasant memories.	1	5	L1_3
d.	I would want the dentist to tell me when I would feel pain.	1	5	L1_4
e.	I would try to sleep.	1	. 5	L1_5
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L1_6
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L1_7
h.	I would do mental puzzles in my mind.	11	5_	L1_8

2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?

		YES	NO	
a.	I would sit by myself and have as many daydreams and fantasies as I could.	1	5	L2_1
b.	I would stay alert and try to keep myself from falling asleep.	1	5	L2_2
c.	I would exchange life stories with the other hostages.	1	5	L2_3
d.	If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.	1	5	L2_4
e.	I would watch every movement of my captors and keep an eye on their weapons.	1	5	L2_5
f.	I would try to sleep as much as possible.	1	5	L2_6
g.	I would think about how nice it's going to be when I get home.	1	5	L2_7
h.	I would make sure I knew where every possible exit was.	1	5	L2_8

3. Imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off has been made and will be announced in several days. Please answer yes or no for each choice.

		YES	NO	
a.	I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	5	L3_1
b.	I would review the list of duties for my present job and try to figure out if I had fulfilled them all.	1	5	L3_2
c.	I would go to the movies to take my mind off things.	1	5	L3_3
d.	I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.	1	5	L3_4
e.	I would push all thoughts of being laid off out of my mind.	1	5	L3_5
f.	I would tell my spouse that I'd rather not discuss my chances of being laid off.	1	5	L3_6
g.	I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	5	L3_7
h.	I would continue doing my work as if nothing special was happening.	1	5	L3_8

4. Imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Please answer yes or no for each choice.

		YES	NO	
a.	I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.	1	5	
b.	I would make small talk with the passenger beside me.	1	5	
c.	I would watch the end of the movie, even if I had seen it before.	1	5	
d.	I would call for the flight attendant and ask her/him exactly what the problem was.	1	5	:
ð.	I would order a drink or tranquilizer from the stewardess.	1	5	.]
f.	I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.	1	5	1
g.	I would talk to the passenger beside me about what might be wrong.	1	5]
h.	I would settle down and read a book or magazine or write a letter.	1	5	1

This set of questions deals with ways you've been coping with the stress in your life that goes with your wife/partner possibly having the altered BRCA1 gene associated with risk for breast cancer. Obviously, different people deal with this stress in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says, how much or how frequently. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7_a.
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4	L7_b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7_c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7_d.
e.	I've been getting emotional support from others.	1	2	3	4	L7_e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7_f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7_g.
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4	L7_h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7_i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7_j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7_k.
1.	I've been trying to come up with a strategy for what to do.	1	2	3	4	L7_1.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7_m.

		I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7
o.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7
).	I've been expressing my negative feelings.	1	2	3	4	L7
] .	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7
	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7
	I've been thinking hard about what steps to take.	1	2	3	4	L7
	I've been praying or meditating.	1	2	3	4	L7
1.	I've been making fun of the situation.	1	2	3	4	L7
	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7
	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L
	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L
	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L
	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L
a.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7
b.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7

6. For each of the statements on the following page, indicate the degree to which this change occurred in your life as a result of your wife/partner possibly having an altered gene associated with greater risk for breast cancer. Please use the following scale:

1 = I experienced no change as a result of my wife/partner possibly having an altered gene associated

with greater risk for breast cancer.

2 = I experienced this change to a <u>very small degree</u> as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.

3 = I experienced this change to a small degree as a result of my wife/partner possibly having an

altered gene associated with greater risk for breast cancer.

4 = I experienced this change to a <u>moderate degree</u> as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.

5 = I experienced this change to a great degree as a result of my wife/partner possibly having an

altered gene associated with greater risk for breast cancer.

6 = I experienced this change to a very great degree as a result of my wife/partner possibly having an

altered gene associated with greater risk for breast cancer.

	·	No Change	Very Small Degree	Small Degree	Moderate Degree	Great Degree	Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6_a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6_b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6_c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6_d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6_e.
f.	Knowing that I can count on people in times of trouble.	1	2	3	4	5	6	L6_f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6_g.
h.	Knowing I can handle difficulties.	1	2	3	4	. 5	6	L6_h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6_i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6_j.
k.	Appreciating each day.	1	2	3	4	5	6	L6_k.
1.	Having compassion for others.	1	2	3	4	5	6	L6_l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6_m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6_n.

Thank you for your valued participation in this study.

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WOMEN'S HEALTH STUDY

Spouse/Partner Questionnaire

Today's Date	
--------------	--

A TT		
A-ID		

SPOP

BACKGROUND DATA SECTION

1.	Date of Birth	Month	Day	Year		A1.
2.	Ethnic Background:	White Hispanic Native Americ	□ 1 □ 2 can □ 3	Black Asian Other	□ 4 □ 5 □ 6	A2.
3.	Religion:	Catholic Jewish Muslim	□ 1 □ 2 □ 3	Protestant Buddhist Other None	□ 4 □ 5 □ 6 □ 7	A3.
		you attend religious an Once a Month		A Few Times A M	onth or More	A3a.
	3b. How importa Not at Al	nt are religious and s l 2 3	•	iefs in your life? Very Im 4 5	•	A3b.
4.	Are you currently work	ting for pay outside	the home?	Yes □ 1	No □ 5	A7.
5.	If <u>ves</u> , about how man	y hours per week ar	e you work	ing for pay?		A8.
	Less than 10 (1)		-30 -33)	31-40 4 (4)	1 or more (5)	
6.	What is the highest level	of education you ha	ave comple	ted? (Check one)		A9.
	 1 □ Less than 9th grade 2 □ Dropped out of hig 3 □ Completed high school 4 □ Some college 	h school	5 □ 6 □ 7 □		ge r professional training nate or professional trainin	ng
	following two question se check the appropriate		t we hope t	hat you will prov	vide this information.	
7.	What is your household (1) Less than \$10,0 (2) \$10,000 to \$19 (3) \$20,000 to \$29	000 (4) \square \$ (5) \square \$	neck one) 330,000 to \$ 340,000 to \$ 550,000 to \$	649,999 (8)		A10.
8.	How many people (adult	s and children) does	this income	e support?		A11.

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagn				rongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

HEALTH SECTION

The following questions concern your wife/partner's risk of developing breast cancer again and of her having the altered gene which has been found to be associated with increased risk for breast cancer. As you may know, breast cancer runs in certain families. In some of these families, persons who develop cancer have an altered version of a gene, BRCA1. Some family members will inherit the gene and others will not.

		Not At All				All The Time	
1.	How often do you worry about your wife/partner again developing breast cancer?	1	2	3	4	5	B2
2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B2
3.	How often do you worry about your wife/partner having the altered gene associated with risk for breast cancer?	1	2	3	4	5	B2
4.	To what extent do worries about your wife/partner having this altered gene interfere with your every day life?	1	2	3	4	5	ВЗ
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5	В3

6. How likely do you think your wife/partner is to develop breast cancer again in the near future?

(Please circle one).

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

7. Overall, what do you believe your wife/partner's risk is of developing breast cancer again at some point in her lifetime?

B10.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

8. Overall, what do you believe your wife/partner's risk is of developing some other cancer unrelated to breast cancer at some point in her lifetime?

B14.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

9. How often does your wife/partner express concern and seek support from you about the risk of breast cancer to herself and women in her family?

B49.

Never	Rarely	Sometimes	Often
1	2	3	4

How much of a burden is this on you? 10.

B50.

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

How often do you discuss genetic testing for breast cancer with your wife/partner? 11.

B51.

Never	Rarely	Sometimes	Often	
1	2	3	4	

When you have these discussions, who generally initiates them? 12.

B52.

You	Your Wife/partner	Equally
1	2	3

13. How satisfied are you with these discussions? B53.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

How often do you and your wife/partner get into a disagreement or conflict over the issue of her getting genetic testing for the risk of breast cancer? 14.

B54.

Never	Never Rarely		Often	
1	2	3	4	

15. Do you think it is beneficial to have genetic testing for risk of breast cancer available to women?

B55.

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

16. Do you want your wife/partner to get genetic testing for risk of breast cancer?

B56.

Not At All	A Little	Somewhat	A Great Deal	
1	2	3	4	

17.	Overall, how muc wife/partner's dec						B57.
		Not At All	A Little	Somewha	t A Gre Deal		
		1	2	3	4		
18.	Overall, how muc wife/partner's dec	h do you want y cisions about v	your opinion to what to do abo	be taken into	account in y for breast ca	our ncer?	B58.
		Not At All	A Little	Somewhat	t A Gre Deal		
		1	2	3	4		
19.	Overall, how important for the altered gen						i B59.
					Deal		
		1	2	3	4		
19a.	Do you believe your	wife has the al	tered gene that	increases the r	risk of breast	cancer?	B60.
19b.	How confident are y	ou in this belie	f?				
	Not At A Confiden				Ve Confid	ery lent	
	1	2 3	4	5	6	7	B61.
20.	Have you attended wife/partner's risk				ome informe	d about your	B62.
		(1)	☐ Yes (5)	□No			
21.	How much contac	t have you had	with medical po	ersonnel conce	erning her ris	k of cancer?	B63.

A Lot

Very Little

22a.	Overa	ll, do you fee cancer and				ned conce	ernir	ng your wife/partner's risk for	B43a.
		Not at All	2	3	4	5	6	Very Much 7	
22b.	Do yo	u feel you are cancer agai		ely inforn	ned abou	ıt your wi	ife/p	artner's risk for developing breast	В43Ь.
		Not at All	2	3	4	5	6	Very Much 7	
22c.	Do yo	u feel you are testing for r				it the bene	efits	and drawbacks of genetic	B44.
		Not at All	2	3	4	5	6	Very Much 7	
22d.	Do you							vife/partner could do personally to BRCA1 gene?	B45.
		Not at All	2	3	4	5	6	Very Much 7	
22e.	Do you	u feel you are options avai						and drawbacks of CA1 gene?	B46.
		Not at All	2	3	4	5	6	Very Much 7	
22f.	Do you					gene?		ld mean for your children if your heck here if you do not have child	B47. ren.
		Not at All	2	3	4	5	6	Very Much 7	C-22f
23.	How c	onfident are	you that y	our wife/	partner:				
	23a.	Will make the associated w				ther to be	test	ed for BRCA1, the altered gene	B48a.
		Not at All	2	3	4	5	6	Very Much 7	
	23b.	Would cope	effective	ly with the	e finding	g that she	had	the altered BRCA1 gene?	В48ь.
		Not at All	2	3	4	5	6	Very Much 7	

23. (continued) How confident are you that your wife/partner: 23c. Would make the best decision concerning her options if she were found to have the altered BRCA1 gene? B48c. Not at All Very Much 7 2 3 5 1 23d. Would be able to follow through with her decisions and cope effectively over the long haul if she were found to have the altered BRCA1 gene? B48d.

Not at All 1 2 3 4 5 6 7

24. Please indicate the extent to which you agree or disagree with the following statements using the 1 (strongly disagree) to 5 (strongly agree) scale. Please try to provide your opinion for all of these questions. However, if you feel you simply do not know enough to have an opinion, check the "I don't know" box.

		Strong Disag	gly ree			trongly Agree	I Don't Know	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	В20с.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.
g.	If a woman were found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5	9	B20m.
h.	Once a woman has had effective treatment for breast cancer, she will not get it again.	1	2	3	4	5	9	B20n.
i.	A mastectomy totally eliminates a woman's risk for breast cancer.	1	2	3	4	5	9	B20o.
j.	All women who have the altered version of the BRCA1 gene will get breast cancer.	1	2	3	4	5	9	B20p.
k.	Most of the breast cancer in the United States is due to altered versions of the BRCA1 gene.	1	2	3	4	5	9	B20q.

		Strong Disagr				rongly Igree	I Don't Know
1.	The next decade is going to bring major advances in the detection and treatment of breast cancer.	1	2	3	4	5	9
m.	Over the next decade, medical break- through's are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9

B20r.

B20s.

If your wife/partner were to take the test and find that she <u>did not</u> have the altered version of the BRCA1 gene which is associated with high risk for breast cancer, what would you expect your reactions to be? 25.

		Strong Disagr	gly ree			rongly Agree	
a.	I would feel wonderful.	1	2	3	4	5	B18a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B18b.
c.	I would feel relieved.	1	2	3	4	5	B18c.
d.	I would not believe the results.	1	2	3	4	5	B18d.
e.	I would fall apart emotionally.	1	2	3	4	5	B18e.
f.	I would feel guilty.	1	2	3	4	5	B18f.
g.	I would still feel anxious.	1	2	3	4	5	B18g.
h.	I would feel angry.	1	2	3	4	5	B18h.
i.	I would feel prepared for the future.	1	2	3	4	5	B18i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B18j.
k.	I would not feel very differently.	1	2	3	4	5	B18k.

26. If your wife/partner were to take the test and find out that she <u>had</u> the altered version of the BRCA1 gene for breast cancer, what would you expect your reactions to be?

		Strong Disagr				rongly Agree	
a.	I would feel relieved about being more certain.	1	2	3	4	5	
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	
c.	I would not believe the results.	1	2	3	4	5	
d.	I would feel guilty.	1	2	3	4	5	
e.	I would feel depressed.	1	2	3	4	5	

b.

d.

e.

		Strong Disagr	gly ree		Si	trongly Agree	
f.	I would feel worried about the future.	1	2	3	4	5	B19f.
g	I would fall apart emotionally.	1	2	3	4	5	B19g.
h.	I would feel anxious.	1	2	3	4	5	B19h.
i.	I would feel angry.	1	2	3	4	5	B19i.
j.	I would not feel very differently.	1	2	3	4	5	B19j.
k.	I would want my daughters to be tested as soon as possible.	1	2	3	4	5	B19k.

27. The following questions concern your involvement in your wife/partner's health care:

		Not at All				Very Often	
a.	To what extent do you go with your wife/partner to her appointments with doctors?	1	2	3	4	5	Н35а.
ъ.	To what extent do you talk with your wife/partner's doctor or other medical personnel about her risk of cancer?	1	2	3	4	5	H35b.
c.	To what extent do you keep track of what your wife/partner needs to do about her risk of cancer?	1	2	3	4	5	Н35с.
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5	H35d.

- 28. If my wife/partner were tested and found to have the altered BRCA1 gene carrying increased risk of breast cancer, I would want her to manage her risk by relying:
 - a. Being extra careful about breast self-examination and regular medical examinations.

Not at All						Very Much So
1	2	3	4	5	6	7

b. Getting preventive surgery.

B64b.

B64a.

Not at All						Very Much So
1	2	3	4	5	6	7

29. I do not believe it would be my place to tell my wife/partner my opinion about what she should do about her risk of breast cancer.

B65.

Strongly Disagree						Strongly Agree
1	2	3	4	5	6	7

RELATIONSHIPS

1.		there anyone in you thout holding back (1) \(\sum \) Yes		m you can shar	e your r	nost	private feelings	C21.
2.	Car	n you share your m	ost private feel	ings with your	wife/par	tner	without holding back?	C21a.
		(1) Yes	(5) 🗆 No					
3.		here anyone beside hout holding back?		tner with whon	n you ca	an sl	nare your most private feelings	C21b.
4.		ve any of the event heck All That A		appened to you	in <u>the</u> j	past	six months?	D1 (a-m)
a.		You retired or wer off from work.	e fired or laid		g.		A close family member was seriously ill or injured.	
b.		You were unemplo			h.		You had a marital separation or divorce.	
c.		Your spouse retire fired or laid off fr			i.		You had serious troubles with relatives or close friends.	
d		Your spouse was and looking for w			j.		Your spouse had troubles with relatives or close	
e.		You had problems police or court.	with the		k.		friends. A close family member died.	
f.		You got into serior difficulties.	us financial		1. m.		A close friend or relative died. You were seriously ill or injured.	

MARRIAGE SECTION

Most people have disagreements in their relationships. Please indicate, using check marks the extent of agreement or disagreement experienced between you and your wife/partner on the following issues **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagree	
1.	Handling family finances	1	2	3	4	5	6	H1.
2.	Matters of recreation	1	2	3	4	5	6	H2.
3.	Religious matters	1	2	3	4	5	6	Н3.
4.	Demonstration of affection	1	2	3	4	5	6	Н4.
5.	Friends	1	2	3	4	5	6	Н5.
6.	Sex relations	1	2	3	4	5	6	Н6.
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	Н7.
8.	Philosophy of life	1	2	3	4	5	6	Н8.
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	Н9.
10.	Aims, goals, and things believed important	1	2	3	4	5	6	H10.
11.	Amount of time spent together	1	2	3	4	5	6	H11.
12.	Making major decisions	1	2	3	4	5	6	H12.
13.	Household tasks	1	2	3	4	5	6	H13.
14.	Leisure time interests and activities	1	2	3	4	5	6	H14.
15.	Career decisions	1	2	3	4	5	6	H15.

		All of the Time	Most of the Time	More Often than Most	Occa- sionally	Rarely	Never	
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5 .	6	H17.
18.	In general, how often do you think that things between you and your wife/partner are going well?	1	2	3	4	5	6	H18.
19.	Do you confide in your wife/partner?	1	2	3	4	5	6	H19.
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6	H21.
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6	Н22.

	Every Day	Almost Every Day	Occa- sionally	Rarely	Never	
23. Do you kiss your wife/partner?	1	2	3	4	5	H23

	All of Them	Most of Them	Some of Them	Very few of Them	None of Them	
24. Do you and your wife/partner engage in outside interests together?	1	2	3	4	5	H24.

How often would you say the following events occur between you and your wife/partner? Less than About About twice a once a twice a Once a More Never month month week dav Often Have a stimulating exchange 25. 1 2 3 4 5 6 of ideas H25. 2 4 5 1 3 6 26. Laugh together H26. 5 1 2 3 4 6 27. Calmly discuss something H27. 2 1 3 4 5 6 28. Work together on a project H28. These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. (Check ves or no). 29. Being too tired for sex. (1) **Yes** (5) No H29. 30. Not showing love. (1) **Yes** (5) No H30. 31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the number which best describes the degree of happiness, all things considered, of your relationship. H31. Extremely Fairly A Little Very Extremely Unhappy Unhappy Unhappy Happy Happy Happy Perfect 1 2 3 7 4 5 6 32. Please check one of the following statements to best describe how you feel H32. about the **future** of your relationship. (1). I want desperately for my relationship to succeed, and would go to almost any length to see that it does. I want very much for my relationship to succeed, and will do all I can to see that it does. (3).___I want very much for my relationship to succeed, and will do my fair share to see that it does. It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed. It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

My relationship can never succeed, and there is no more that I

can do to keep the relationship going.

33. Considering only the positive feelings you have toward your wife/partner, and ignoring the negative ones, please rate how positive these feelings are:

H33.

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

34. Considering only the negative feelings you have toward your wife/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

CURRENT FAMILY SECTION

Please indicate the extent to which each of the following items describes your current family (your household).

		Strong Disag				trongly Agree		
1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.	
2.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.	
3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	М3.	
4.	Individuals are accepted for who they are.	1	2	3	4	5	M4.	
5.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.	
6.	We can express feelings to each other.	1	2	3	4	5	M6.	
7.	There are lots of bad feelings in the family.	1	2	3	4	5	М7.	
8.	We feel accepted for who we are.	1	2	3	4	5	М8.	
9.	Making decisions is a problem for our family.	1	2	3	4	5	М9.	
10.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.	
11.	We don't get along well together.	1	2	3	4	5	M11.	
12.	We confide in each other.	1	2	3	4	5	M12.	

YOUR HEALTH AND MOOD SECTION

1.	In gen	eral, would	you say yo	our health is:				I1.
	(1)	Excellent	(2) 🗆 V	ery Good	(3) Good	(4) 🗆 Fai	r (5) [□ Poor
2.	you fe	lt sad, blue,	or depress		eks or more when ne th you lost all interest to for fun?		vork	I14.
		(1)	□ Yes	(5) 🗆 No (S	kip to Question 3)			
	2a.	If there was	as such a tv	wo-week peri	od, did your work or	relationships		I14a.
		(1)	□ Yes	(5) 🗆 No				
	2b.	If there was		wo-week peri	od, did you get couns	seling or		I14b.
		(1)	□ Yes	(5) 🗆 N o				
	2c.	If there w condition?		wo-week per	iod, did you get medi	cation for this		I14c.
		(1)	□ Yes	(5) 🗆 No				
3.	you fe	elt sad, blue,	or depress		weeks or more whe th you lost all interest to for fun?			I12.
		(1)	☐ Yes	(5) 🗆 No (S	kip to Question 4)			
	3a.	If there we or relation			riod (in the past 6 r	nonths), did yo	ur work	I12a.
		(1)	□ Yes	(5) 🗆 No				
	3b.	If there we counseling			riod (in the past 6 r	nonths), did yo	u get	I12b.
		(1)	☐ Yes	(5) 🗆 N o				
	3c.	If there we medication			riod, (in the past 6	months) did yo	u get	I12c.
		(1)	□ Yes	(5) 🗆 N o				
4.		ou currently ssion or emo			psychotherapy, or m	edication for		I13.
		(1)	□ Yes	(5) □ N o				

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		1 Not at all	2 A little	3 Quite a bit	4 Extremely	
1.	Suddenly scared for no reason	1	2	3	4	
2.	Feeling fearful	1	2	3	4	
3.	Faintness, dizziness, or weakness	1	2	3	4	
4.	Nervousness or shakiness inside	1	2	3	4	
5.	Heart pounding or racing	1	2	3	4	
6.	Trembling	1	2	3	4	
7.	Feeling tense or keyed up	1	2	3	4	
8.	Headaches	1	2	3	4	
9.	Spells of terror or panic	1	2	3	4	
10.	Feeling restless, can't sit still	1	2	3	4	F
11.	Feeling low in energyslowed down	1	2	3	4	F
12.	Blaming yourself for things	1	2	3	4	F
13.	Crying easily	1	2	3	4	F
14.	Loss of sexual interest or pleasure	1	2	3	4	F
15.	Poor appetite	1	2	3	4	F
16.	Difficulty falling asleep, staying asleep	1	2	3	4	F
17.	Feeling hopeless about the future	1	2	3	4	F
18.	Feeling blue	1	2	3	4	F
19.	Feeling lonely	1	2	3	4	F
20.	Feeling trapped or caught	1	2	3	4	F
21.	Worrying too much about things	1	2	3	4	F
22.	Feeling no interest in things	1	2	3	4	Ŀ
23.	Thoughts of ending your life	1	2	3	4	F
24.	Feeling everything is an effort	1	2	3	4	F
25.	Feelings of worthlessness	1	2	3	4	K

COPING SECTION

1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Please answer yes or no for each choice.

		YES	NO	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L1_1
b.	I would take a tranquilizer or have a drink before going.	1	5	L1_2
c.	I would try to think about pleasant memories.	1	5	L1_3
d.	I would want the dentist to tell me when I would feel pain.	1	5	L1_4
e.	I would try to sleep.	1	5	L1_5
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L1_6
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L1_7
h.	I would do mental puzzles in my mind.	1	5	L1_8

2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?

		YES	NO	
a.	I would sit by myself and have as many daydreams and fantasies as I could.	1	5	L2_1
b.	I would stay alert and try to keep myself from falling asleep.	1	5	L2_2
c.	I would exchange life stories with the other hostages.	1	5	L2_3
d.	If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.	1	5	L2_4
e.	I would watch every movement of my captors and keep an eye on their weapons.	1	5	L2_5
f.	I would try to sleep as much as possible.	1	5	L2_6
g.	I would think about how nice it's going to be when I get home.	1	5	L2_7
h.	I would make sure I knew where every possible exit was.	1	5	L2_8

3. Imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off has been made and will be announced in several days. Please answer yes or no for each choice.

		YES	NO	
a.	I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	5	L3_1
b.	I would review the list of duties for my present job and try to figure out if I had fulfilled them all.	1	5	L3_2
c.	I would go to the movies to take my mind off things.	1	5	L3_3
d.	I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.	1	5	L3_4
e.	I would push all thoughts of being laid off out of my mind.	1	5	L3_5
f.	I would tell my spouse that I'd rather not discuss my chances of being laid off.	1	5	L3_6
g.	I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	5	L3_7
h.	I would continue doing my work as if nothing special was happening.	1	5	L3_8

4. Imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Please answer yes or no for each choice.

		YES	NO	
a.	I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.	1	5	L4_1
b.	I would make small talk with the passenger beside me.	1	5	L4_2
c.	I would watch the end of the movie, even if I had seen it before.	1	5	L4_3
d.	I would call for the flight attendant and ask her/him exactly what the problem was.	1	5	L4_4
e.	I would order a drink or tranquilizer from the stewardess.	1	5	L4_5
f.	I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.	1	5	L4_6
g.	I would talk to the passenger beside me about what might be wrong.	1	5	L4_7
h.	I would settle down and read a book or magazine or write a letter.	1	5	L4_8

5. This set of questions deals with ways you've been coping with the stress in your life that goes with your wife/partner possibly having the altered BRCA1 gene associated with risk for breast cancer. Obviously, different people deal with this stress in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says, how much or how frequently. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a. I've been turning to work or other activities to take my mind off things.	1	2	3	4
I've been concentrating my efforts on doing something about her situation.	1	2	3	4
I've been saying to myself "this isn't possible."	1	2	3	4
d. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
e. I've been getting emotional support from others.	1	2	3	4
I've been giving up trying to deal with it.	1	2	3	4
I've been taking action to try to make the situation better.	1	2	3	4
I've been refusing to believe that it is possible she has the gene.	1	2	3	4
. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
I've been trying to come up with a strategy for what to do.	1	2	3	4

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7_
n.	I've been giving up the attempt to cope.	1	2	3	4	L7.
о.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7.
p.	I've been expressing my negative feelings.	1	2	3	4	L7 ₋
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7_
r.	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7_
t.	I've been praying or meditating.	1	2	3	4	L7.
u.	I've been making fun of the situation.	1	2	3	4	L7_
٧.	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7_
W .	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L7.
κ.	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L7
y.	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L7
z.	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L7
ıa.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7_
bb.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7_

cance	er:										
6.		our worst, ho		sed did yo	ou feel	about yo	ur wife	e/partner's o	liagnosis		L8.
		Not at All	2	3	4	5	6	Very Much 7			
7.	blue,	ng that time, d or depressed s you usually	or in which	h you lost	t all inte	erest in th	ings li		hobbies or		L9.
	a.	If there was	s such a tw		period,		work o			,	L9a.
	b.	If there was		o-week p				nseling or			L9b.
	c.	If there w	vas such a		•	l, did you (5) 🗆 N d	_	edication fo	r this prob	lem?	L9c.
8.	life a	ach of the stat s a result of your	our wife/pa	artner bei						hange occurre	ed in you
	1 =	I experienced	l <u>no</u> chang	e as a res	ult of m	y wife/p	artner's	being diag	nosed and	treated for car	ncer.
	2 =	I experienced and treated for		ge to a <u>v</u> e	ery sm	all degre	e as a	result of my	wife/part	ner's being di	agnosed
	3 =	I experienced and treated fo		ge to a <u>sr</u>	nall de	gree as a	result	of my wife	/partner's l	peing diagnos	ed
	4 =	I experienced and treated fo		ge to a <u>m</u>	oderat	<u>e degree</u>	as a re	esult of my	wife/partn	er's being dia	gnosed
	5 =	I experienced and treated for		ge to a gr	eat de	gree as a	result	of my wife	partner's b	eing diagnose	ed
	6 =	I experienced and treated fo		ge to a ve	ery gre	at degre	e as a 1	result of my	wife/part	ner's being di	agnosed
□ Doe	es not	apply because	I was not	with my	wife/pa	artner wh	en she	was being t	reated for	breast cancer.	L6

The following questions concern coping with your wife/partner's diagnosis and treatment for

		No Change	Very Small Degree	Small Degree	Moderate Degree	Great Degree	Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6_a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6_b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6_c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6_d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6_e.
f.	Knowing that I can count on people in times of trouble.	1	2	3	4	5	6	L6_f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6_g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6_h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6_i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6_j.
k.	Appreciating each day.	1	2	3	4	5	6	L6_k.
1.	Having compassion for others.	1	2	3	4	5	6	L6_1.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6_m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6_n.

- 9. During the time in which your wife/partner was being treated for breast cancer, how often did you do the following to help her manage the emotional distress?
 - ☐ Does not apply because I was not with my wife/partner when
 - (-8) she was being treated for breast cancer.

		Never				Very Often	i
1.	Gave her advice?	1	2	3	4	5	L10a.
2.	Went out of your way not to upset her?	1	2	3	4	5	L10b.
3.	Agreed with her to avoid an argument?	1	2	3	4	5	L10c.
4.	Acted more optimistic than you felt?	1	2	3	4	5	L10d.
5.	Kept your own problems to yourself?	1	2	3	4	5	L10e.
6.	Made up after an argument more quickly than before?	1	2	3	4	5	L10f.
7.	Apologized even when you didn't feel you were wrong?	1	2	3	4	5	L10g.
8.	Told her to calm down or relax?	1	2	3	4	5	L10h.
9.	Hid information that may upset her?	1	2	3	4	5	L10i.
10.	Stayed out of her problems?	1	2	3	4	5	L10j.
11.	Let your own problems take a "back seat" to her needs?	1	2	3	4	5	L10k.
12.	Gave her space when she was upset?	1	2	3	4	5	L101.

We thank you for all of your valued participation in this study.

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WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

TODAY'S DATE					ID		
			PRE-I	RESULTS ASS	SESSMENT - U	J	
new.	We are a		in because we			onnaires, but many of tittudes which may cha	
		<u>(</u>	ENETIC	TESTIN	NG-SECT	CION 1	
1. Have you met with anyone to have genetic counseling? (1) □ Yes (5) □ No							B24.
 Has any member of your family met with someone to have genetic counseling? (1) □ Yes (5) □ No 							B25.
3.	As the	opportunity to	get testing has	approached, has	s your interest i	n getting results change	ed? B74 .
		Decreased Very Much	Decreased Slightly 2	No Change 3	Increased Slightly 4	Increased Very Much 5	
 4. At this time, what is your decision regarding receiving your genetic results? I will probably or definitely receive my results now, as soon as they are offered. (Skip to Question 4) (3) □ I do not intend to receive my results now, but may do so later. (Skip to Question 5) (5) □ I do not intend to receive my results now or in the future. (Skip to Question 6) 							estion 5)
5.	to you, (Pleas	, what are your se check all t	reasons for doi hat apply <u>an</u>	ng so? d then circle	the number	as they are being offer of the statement g your results now	B113.
	(1)	I just want to	know whether	r I have the gen	e. I am happie	r knowing.	
	(2)			o get prophylac	ctic surgery.		
	(3)		in other medic				
	(4)		isions about fa	• • •			
	(5)		•	nancial planning			
	(6)		•	non-medical de			
	(7)			y be transmitted	l to my children	l . .	
	(8)	•	bers want me to				
	(9)			members by pro		*	
	(10)	Other (please	e describe)				

6.	•	do <u>not</u> intend to obtain your results <u>now</u> , but may do so <u>later</u> , please indicate your B114.
		s. the check all that apply and then circle the number of the statement which indicates most important reason for delaying receiving your results).
	(1) 🗔	I am happier not knowing.
	(2)	There are no decisions I need to make at this time for which knowledge of my results would be
		useful.
	(3)	It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
	(4)	Knowing that I have a mutation would interfere with my life as it is now.
	(5)	There would not be much I could now do to reduce my risk of cancer if I found out I had a
		mutation.
	(6)	I am too worried about the effects of knowing my results on women in my family.
	(7)	Family members do not want me to get testing.
	(8)	Family members want me to get testing, but I am not ready to do so.
	(9)	I want to wait until there is less risk to insurance coverage.
	(10)	I want to wait until there is less risk to employment.
	(11)	I am either too young or too old to benefit from knowing if I have a mutation.
	(12)	I want to wait until more is known about breast/ovarian cancer genes and what can be done to
		reduce a women's risk of cancer.
	(13)	I simply am not ready to make up my mind at this time.
	(14)	Other (please describe)
7.	(Please	do <u>not</u> intend to obtain your results <u>now or in the future</u> , please indicate your reasons. B115. e check all that apply <u>and</u> then circle the number of the statement indicates your most important reason for not receiving your results).
	(1)	I am happier not knowing.
	(2)	There are no decisions I need to make for which knowledge of my results would be useful.
	(3)	It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
	(4)	Knowing that I have a mutation would interfere with my life.
	(5)	There would not be much I could do to reduce my risk of cancer if I found out I had a mutation.
	(6)	I am too worried about the effects of knowing my results on women in my family.
	(7)	Family members do not want me to get testing.
	(8)	Risk to my insurance coverage.
	(9)	Risk to my employment.
	(10)	I am either too young or too old to benefit from knowing if I have a mutation.
	(11)	I do not believe in obtaining personal genetic information.
	(12)	Other (please describe)

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disag				trongly Agree	
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

Using the following scales, please circle your response for each question.

						Not	
	Not At	All		Very		cable	
How distressing is it for you to know that you may be at increased risk for breast or ovarian cancer because of your family history?	1	2	3	4	5	-8	B66.
How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer?	1	2	3	4	5	-8	B67.
How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)?	1	2	3	4	5	-8	B68.
How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene?	1	2	3	4	5	-8	B69.
How distressed would you be if you took the test and found that you did not have an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8	В70.
Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/BRCA2 gene?	1	2	3	4	5	-8	B71.
	be at increased risk for breast or ovarian cancer because of your family history? How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer? How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? How distressed would you be if you took the test and found that you did not have an altered BRCA1/BRCA2 gene? Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/	How distressing is it for you to know that you may be at increased risk for breast or ovarian cancer because of your family history? How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer? How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? How distressed would you be if you took the test and found that you did not have an altered BRCA1/BRCA2 gene? Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/	be at increased risk for breast or ovarian cancer because of your family history? How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer? How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/	How distressing is it for you to know that you may be at increased risk for breast or ovarian cancer because of your family history? How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer? How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? How distressed would you be if you took the test and found that you had an altered BRCA-1/ BRCA2 gene? Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/	How distressing is it for you to know that you may be at increased risk for breast or ovarian cancer because of your family history? How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer? How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/	How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2 gene? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? Not At All Very Much 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 3 5 1 3 4 5 1 5 5 1 5 5 5 1 5 6 7 7 8 7 8 7 8 7 8 7 8 7 8 7 8 7 8 7 8	How distressing is it for you to know that you may be at increased risk for breast or ovarian cancer because of your family history? How distressing is it to be given the opportunity to be tested for an altered BRCA-1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer? How distressed do you expect to be if you get tested for an altered BRCA-1/BRCA2 gene (just before you receive results)? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? How distressed would you be if you took the test and found that you had an altered BRCA-1/BRCA2 gene? Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA-1/

		Not At	All		All T	he Time	
7.	How often do you worry about developing breast or ovarian cancer?	1	2	3	4	5	B27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
9.	How often do you worry about having an altered gene which conveys heightened risk for breast and ovarian cancer?	1	2	3	4	5	B29.
10.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.

11.	When was the last time you had a mar	mmogram?	B32.
	(Month/Year)	☐(-8) Does not apply because of surgery.	

12.	How	many times h	ave you	u conduct	ed a brea	st self-ex	kaminatio	n in the past six months?	В33.
			times		□(-8) ː	Does not a	apply becar	use of surgery.	
13.	How	confident are	you th	at you wil	l perforn	n breast s	self exami	ination (BSE)	
	13a.	as freque	ently as	s needed?	(-8) 🗆 D	oes Not A	pply Becau	use of Surgery.	B34a.
		Not at All	2	3	4	5	6 V	ery Much So	
	13b.	as carefu	ılly an	d compe				use of Surgery	B34b.
		Not at All	2	3	4	5	6 V	Very Much So	

For each of the following areas of your life, we ask you to make <u>two</u> ratings. First, indicate how much these decisions have been affected by <u>being at risk for breast or ovarian cancer</u> (based on your family history). Second, how much these decisions would be affected by <u>the results of genetic testing</u>?

N	ot at all affected								Very	much	affecte	ed
			Have been affected by being at risk for breast or ovarian cancer Would be affected by the results of genetic testing									
14.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
15.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
16.	Decisions about which steps to take to prevent the occurrence of breast or ovarian cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
17.	Decisions about work and career	1	2	3	.4	5	1	2	3	4	5	B38a B38b
18.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
19.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

Answer the following question only if you have daughters. 20.

☐ Does Not Apply (Skip to the next question, 22)

B41.

		Have been affected by being at high risk for breast or ovarian cancer				Would be affected by the results of genetic testing						
a-b.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42 a/b

21. Do you feel you have enough information about breast or ovarian cancer to make any decisions that might be necessary?

Not At All										
1	2	3	4	5	6	7				

22. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast and ovarian cancer?

Not At All									
1	2	3	4	5	6	7			

B44.

B45.

B43.

23. Do you feel you are adequately informed about what you could do to reduce your risk of breast and ovarian cancer if you had an altered BRCA1/BRCA2 gene?

Not At	Not At								
All	All								
1	2	3	4	5	6	7			

24. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	B46.
1	2	3	4	5	6	7	

25. Do you feel you are adequately informed about what it would mean for your children if you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B47.

26. How confident are you that you will make the best decision in deciding whether to be tested for BRCA1/BRCA2?

Not At All									
1	2	3	4	5	6	7			

27. How confident are you that you would cope effectively with a finding that you had an altered BRCA1/BRCA2 gene?

Not At All						B48b.	
1	2	. 3	4	5	6	7	

28. How confident are you that you would make the best decision concerning your options if you were found to have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	B48c.
1	2	3	4	5	6	7	

29. How confident are you that you would be able to follow through and cope effectively over the long haul if you were found to have an altered BRCA1/BRCA2 gene?

Not At All							B48d.
1	2	- 3	. 4	5	6	7	

RELATIONSHIPS SECTION

1.		ere anyone in your life with whom you can sl lout holding back?	nare you	most p	rivate feelings	C21.
	Wiu	(1) \(\sum \) Yes (5) \(\sum \) No				
2.		arried, can you share your most private feelining back? (1) Yes (5) No	gs with y	your spo	ouse/partner without	C21a.
3.	If may	arried, is there anyone besides your spouse/parried, is there are anyone besides your spouse/parried, is the parried in the pa	artner wi	th whor	n you can share	C21b.
		$(1) \square Yes \qquad (5) \square No$				
1.	Have (Ple	e any of the following events happened to you ase Check All That Apply)				D1(a-m)
a.		You retired, were fired, or laid off from work.	g.		A close family member vill or injured.	vas seriously
b.		You were unemployed and looking for work.	h. i.		You had a marital separa You had serious troubles	
C.		Your spouse retired, was fired, or laid off from work.	j.		or close friends. Your spouse had troubles	
d		Your spouse was unemployed and looking for work.	k.		with relatives or close fri A close family member d	
e.		You had problems with the police or court.	1.		A close friend or relative You were seriously ill or	died.
f.		You got into serious financial difficulties.	m.		I ou were seriously in or	mjureu.

MARRIAGE SECTION

The following questions apply to persons who are <u>married or living with</u> a partner. If you are not married or living with a partner, please check the box and skip to page 11, Mood Section.

Not married or living with a partner \square	Not married or living with a partner	□ E	а
--	--------------------------------------	-----	---

Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH**.

-		Always Disagree	Almost Always Disagree	Fre- quently Disagree	Occa- sionally Disagree	Almost Always Agree	Always Agree	
1.	Religious matters	1	2	3	4	5	6	Н3.
2.	Demonstration of affection	1	2	3	4	5	6	H4.
3.	Sex relations	1	2	3	4	5	6	Н6.
4.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	Н7.
5.	Making major decisions	1	2	3	4	5	6	H12.
6.	Career decisions	1	2	3	4	5	6	H15.

		Never	Rarely	Occa- sionally	More often than most	Most of the time	All of the time	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
8.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
9.	How often do you and your partner quarrel?	1	2	3	4	5	. 6	H21.
10.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

	None of	Very Few	Some of	Most of	All of
	Them	of Them	Them	Them	Them
To what extent do you and your spouse/partner share interests together?	1	2	2	4	5

H24.

How often would you say the following events occur between you and your spouse/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

Considering only the positive feelings you have towards your spouse/partner, and ignoring the negative ones, please rate how positive these feelings are: 15.

H33.

Not A Posi									emely sitive
1	2	3,	4	5	6	7	8	9	10

Considering only the negative feelings you have towards your spouse/partner, 16. and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Nega									remely gative
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your spouse/partner's involvement in your health care.

		Never				Very Often	
a.	How often does your spouse/partner go with you to your appointments with doctors?	1	2	3	4	5	H35
b.	How often does your spouse/partner talk with your doctor or other medical personnel about your risk for breast or ovarian cancer?	1	2	3	4	5	Н35
c.	How often does your spouse/partner keep track of what you need to do about your risk for breast or ovarian cancer?	1	2	3	4	5	Н35
d.	How often does your spouse/partner change their activities to assist you in your health care?	1	2	3	4	5	Н35

5a.

5b.

5c.

5d.

18.	Has y inform	our spouse/pa ned about you	artner atte ar risk for (1) []	breast of	lividual, t r ovarian (5) □ N	cancer	or group and wh	p sessions to become nat can be done?	Н36.
19.	How for br	much contact east or ovarian	has your n cancer?	spouse/p	artner ha	d with 1	medica	l personnel concerning your risk	Н37.
		Very Little or None 1	2	3	4	5	6	A lot	
20.	Do yo	ou feel your sp r and what car	ouse/part be done	tner is ad about it?	equately	informe	ed conc	cerning your risk for breast or ovarian	Н38.
		Not at All	2	3	4	5	6	Very Much 7	
21.	To wh	nat extent are g care?	you satisf	fied with	your spo	use/par	tner's ii	nvolvement in your	Н39.
		Not at All	2	3	4	5	6	Very Much	
				M	OOD	SE(TTI) NI	
					<u>OOD</u>				
1.	blue, c	past year, has or depressed of the liked to do for the liked to do	<u>r</u> in whic	n you los	veeks or st all inte	rest in t	hings li	early every day you felt sad, ike work or hobbies or things you	I12.
			(1)	103	(3) 🗀 140	(Skip i	o Ques	suon 2)	
	1a.	During this I	period, di Yes	d your w (5) 🗆 N		lationsh	nips suf	ffer?	I12a.
	1b.	During this p	period, di Yes	d you get (5) \square N	t counsel Io	ing or p	sychot	herapy?	I12b.
	1c.	During this p (1) □	eriod, die Yes	d you get (5) \square N	medicat Io	ion for 1	this cor	ndition?	I12c.
2.	Are yo	ou currently rotional problem	eceiving ns?	counseli	ng, psycl	notherap	y, or n	nedication for depression	I13.
		(1)	Yes	(5) 🗆 N	О				

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You

During the Past Three Months.

During	g the <u>Last Three Montres</u> .	Not at all	<u>A little</u>	Quite a bit	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	11	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2 .	3	4	K3.
4.	Nervousness or shakiness inside	11	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	К9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1 .	2	3	4	K20.
21.	Worrying too much about things	11	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	11	2	3	4	K24.
25.	Feelings of worthlessness	11	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast or ovarian cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast or ovarian cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	.5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
1.	Having compassion for others.	1	2	3	4	5	6	L61.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast or ovarian cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says, how much or how frequently. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Please make your answers as true FOR YOU as you can.

		I haven't been doing this at all	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	
c.	I've been saying to myself "this isn't possible."	1	2	3	4	
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	
ð.	I've been getting emotional support from others.	1	2	3	4	
f.	I've been giving up trying to deal with it.	1	2	3	4	
g.	I've been taking action to try to make the situation better.	1	2	3	4]
1.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4]
	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	
	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	
۲.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4]
	I've been trying to come up with a strategy about what to do.	1	2	3	4	
m.	I've been getting comfort and understanding from someone.	1	2	3	4	I

	·	I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
n.	I've been giving up the attempt to cope.	1	2	3	4
ο.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4
p.	I've been expressing my negative feelings.	1	2	3	4
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s.	I've been thinking hard about what steps to take.	1	2	3	4
t.	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

3. The following items are to be answered only by those women who are <u>married or living with a partner</u>.

□ Not married or living with a partner

(Skip to the last section on next page)

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4
b.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4
c.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4
d.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4

L8a.

L8b.

L8c.

L8d.

BACKGROUND DATA SECTION

These are a few questions about your religious background that we forgot to ask on the original questionnaire.

1.	Religion	:	Catholic Jewish Muslim	(1)	Protestant Buddhist Other None	(4) □ (5) □ (6) □ (7) □	A3.
	1a.	How often do y (1) Less Often T		(5))	A Month or More	A3a.
	1b.	How important	are religious a	and spiritual l	beliefs in your li	fe?	A3b.
		Not at All	2	3	Ver	ry Important 5	

Once again, We thank you for all of your valued participation in this study.





WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

TODA	Y'S DA	TE				ID							
PRE-RESULTS QUESTIONNAIRE - A													
new. V	Ve are a	ce that some of asking them aga	ain because we	were asked in are interested ir	previous questi feelings and a	onnaires, but m ttitudes which n	any of the quentary change over	stions are er time.					
		(GENETIC	TESTI	NG-SECT	TON 1							
1.													
2.	 Has any member of your family met with someone to have genetic counseling? (1) □ Yes (5) □ No 												
3.	As the	opportunity to	get testing has	approached, has	s your interest is	n getting results	changed?	B74.					
		Decreased Very Much	Decreased Slightly 2	No Change 3	Increased Slightly 4	Increased Very Much 5							
4.	At this	(1) ☐ I will I (Skip t	to Question 4) of intend to rece	initely receive r	ny results now,	as soon as they o so later. (Skip	to Question 5	B112.					
	to you, (Pleas	will probably o what are your se check all t	r definitely obta reasons for doi hat apply an	nin your results ng so? d then circle	now, as soon	as they are beir of the statement your results	ng offered	B113.					
	(1)		know whether			r knowing.							
	(2)		ecide whether t		tic surgery.								
	(3)		in other medic										
	(4)		cisions about far	• •									
	(5)		cisions about fir			•	•						
	(6)		style and other										
	(7)		he risk that may		to my children	•							
	(8)	•	bers want me to	•									
	(9) 🗌	I want to hel	p other family i	nembers by pro	9) I want to help other family members by providing them with my results.								

Other (please describe)

(10)

6.	reason	
		e check all that apply <u>and</u> then circle the number of the statement which indicates most important reason for delaying receiving your results).
	(1)	I am happier not knowing.
	(2)	There are no decisions I need to make at this time for which knowledge of my results would be
		useful.
	(3)	It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
	(4)	Knowing that I have a mutation would interfere with my life as it is now.
	(5)	There would not be much I could now do to reduce my risk of cancer if I found out I had a
		mutation.
	(6)	I am too worried about the effects of knowing my results on women in my family.
	(7)	Family members do not want me to get testing.
	(8)	Family members want me to get testing, but I am not ready to do so.
	(9)	I want to wait until there is less risk to insurance coverage.
	(10)	I want to wait until there is less risk to employment.
	(11)	I am either too young or too old to benefit from knowing if I have a mutation.
	(12)	I want to wait until more is known about breast/ovarian cancer genes and what can be done to
		reduce a women's risk of cancer.
	(13)	I simply am not ready to make up my mind at this time.
	(14)	Other (please describe)
7.	(Please	do <u>not</u> intend to obtain your results <u>now or in the future</u> , please indicate your reasons. B115. e check all that apply <u>and</u> then circle the number of the statement indicates your most important reason for not receiving your results).
	(1)	I am happier not knowing.
	(2)	There are no decisions I need to make for which knowledge of my results would be useful.
	(3)	It would be too upsetting to learn that I have a mutation associated with increased risk of cancer.
	(4)	Knowing that I have a mutation would interfere with my life.
	(5)	There would not be much I could do to reduce my risk of cancer if I found out I had a mutation.
	(6)	I am too worried about the effects of knowing my results on women in my family.
	(7)	Family members do not want me to get testing.
	(8)	Risk to my insurance coverage.
	(9)	Risk to my employment.
	(10)	I am either too young or too old to benefit from knowing if I have a mutation.
	(11)	I do not believe in obtaining personal genetic information.
	(12)	Other (please describe)

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		Strong Disagr					
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
1.	I hardly ever expect things to go my way.	1	2.	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
0.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

Using the following scales, please circle your response for each question.

	· · · · · · · · · · · · · · · · · · ·						Not Appli-	
		Not At	All		Very	Much	cable	
1.	How distressing is it for you to know that you may be at increased risk for recurrence of breast or ovarian cancer because of your family history?	1	2	3	4	5	-8	B66.
2.	How distressing is it to be given the opportunity to be tested for an altered BRCA1/BRCA2, the altered genes associated with increased risk for breast and ovarian cancer?	1	2	3	4	5	-8	B67.
3.	How distressed do you expect to be if you get tested for an altered BRCA1/BRCA2 gene (just before you receive results)?	1	2	3	4	5	-8	B68.
4.	How distressed would you be if you took the test and found that you had an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8	B69.
5.	How distressed would you be if you took the test and found that you did not have an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8	B70.
6.	Overall, to what extent do you welcome the opportunity to be tested for an altered BRCA1/BRCA2 gene?	1	2	3	4	5	-8	B71.

			All		All T	he Time	
7.	How often do you worry about again developing breast or ovarian cancer?	1	2	3	4	5	B27.
8.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
9.	How often do you worry about having an altered gene which conveys heightened risk for breast and ovarian cancer?	1	2	3	4	5	B29.
10.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.

11.	When was the last time you had a mammogram?						
	(Month/Year)	□(-8) Does not apply because of surgery.					

12.	How many times have you conducted a breast self-examination in the past six months?					В33.			
	times								
13.	How	confident are	you tha	at you will	perforn	n breast s	elf exami	nation (BSE)	
	13aas frequently as needed? (-8) □ Does Not Apply Because of Surgery.							B34a.	
		Not at All	2	3	4	5	6 V	ery Much So	
	13bas carefully and competently as needed? (-8) □ Does Not Apply Because of Surgery						use of Surgery	B34b.	
		Not at All	2	3	4	5	۷ 6	Very Much So	

For each of the following areas of your life, we ask you to make <u>two</u> ratings. First, indicate how much these decisions have been affected by <u>being at increased risk for breast or ovarian cancer</u> (based on your family history). Second, how much these decisions would be affected by <u>the results of genetic testing</u>?

N	1 2 ot at all affected	,			3		4		Very	5 much	affecte	ed
			been creased ovai		for bre		Would be affected by the results of genetic testing					
14.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35 B35
15.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36
16.	Decisions about which steps to take to prevent the recurrence of breast or ovarian cancer	1	2	3	4	5	1	2	3	4	5	B3'
17.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38
18.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	. 4	5	B39
19.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40 B40

20. Answer the following question only if you have daughters.

☐ Does Not Apply (Skip to the next question, 22)

B41.

			high r	affecte isk for ian ca	breast					ted by tic test		
a-b.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42 a/b

21. Do you feel you have enough information about breast or ovarian cancer to make any decisions that might be necessary?

Not At All						Very Much
1	2	3	4	5	6	7

22. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast and ovarian cancer?

Not At All						Very Much
1	2	3	4	5	6	7

B44.

B43.

23. Do you feel you are adequately informed about what you could do to reduce your risk of recurrence of breast and ovarian cancer if you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much	B45.
1	2	3	4	5	6	7	

24. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	В46.
1	2	3	4	5	6	7	

25.	Do you feel you are adequately informed about what it would mean for your children
	if you had an altered BRCA1/BRCA2 gene?

Not At All	·					Very Much
1	2	3	4	5	6	7

26. How confident are you that you will make the best decision in deciding whether to be tested for BRCA1/BRCA2?

Not At All						Very Much	B48a.
1	2	3	4	5	6	7	

B47.

27. How confident are you that you would cope effectively with a finding that you had an altered BRCA1/BRCA2 gene?

Not At All						Very Much	В48Ь.
1	2	3	4	5	6	7	

28. How confident are you that you would make the best decision concerning your options if you were found to have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	B48c.
1	2	3	4	5	6	7	

29. How confident are you that you would be able to follow through and cope effectively over the long haul if you were found to have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	B48d.
1	2	3	4	5	6	7	

RELATIONSHIPS SECTION

1.	Is the with	re anyone in your life with who out holding back?	om you can sha	are your	most p	rivate feelings	C21.
		(1) ☐ Yes	(5) \(\sum \text{No} \)				
2.		rried, can you share your most ng back?	private feeling	gs with y	our spo	use/partner without	C21a.
3.		rried, is there anyone besides y most private feelings without he		rtner wi	th whon	n you can share	C21b.
		(1) \square Yes	(5) 🗆 No				
1.		any of the following events hase Check All That Apply)					D1(a-m)
a.		You retired, were fired, or la from work.	id off	g.		A close family member was ill or injured.	seriously
b.		You were unemployed and lo	ooking for	h.		You had a marital separation	
c.		work. Your spouse retired, was fire	ed, or	i.		You had serious troubles wi or close friends.	
d		laid off from work. Your spouse was unemploye	d and	j.		Your spouse had troubles or with relatives or close friend	
ů.		looking for work.		k.		A close family member died	
e.		You had problems with the p court.	olice or	1.		A close friend or relative die	
f.		You got into serious financia	l difficulties.	m.		You were seriously ill or inj	urea.

MARRIAGE SECTION

The following questions apply to persons who are <u>married or living with</u> a partner. If you are not married or living with a partner, please check the box and skip to page 11, Mood Section.

Not married or living with a partner \square

Ea.

Most people have disagreements in their relationships. Please indicate by circling the number that represents the extent of agreement or disagreement experienced between you and your spouse/partner **DURING THE PAST MONTH**.

		Always Disagree	Almost Always Disagree	Fre- quently Disagree	Occa- sionally Disagree	Almost Always Agree	Always Agree	
1.	Religious matters	1	2	3	4	5	6	Н3.
2.	Demonstration of affection	. 1	2	3	4	5	6	Н4.
3.	Sex relations	1	2	3	4	5	6	Н6.
4.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	Н7.
5.	Making major decisions	1	2	3	4	5	6	H12.
6.	Career decisions	1	2	3	4	5	6	H15.

		Never	Rarely	Occa- sionally	More often than most	Most of the time	All of the	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	. 1	2	3	4	5	6	H16.
8.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
9.	How often do you and your partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your spouse/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		None of Them	Very Few of Them	Some of Them	Most of Them	All of Them
11.	To what extent do you and your spouse/partner share interests together?	1	2	3	4	5

H24.

How often would you say the following events occur between you and your spouse/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1 .	2	3	4	5	6

H25.

H27.

H28.

15. Considering only the positive feelings you have towards your spouse/partner, and ignoring the negative ones, please rate how positive these feelings are:

Н33.

Not A Posi									remely sitive
1	2	3	4	5	6	7	8	9	10

16. Considering only the negative feelings you have towards your spouse/partner, and ignoring the positive ones, please rate how negative these feelings are:

H34.

Not A Negat									emely gative
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your spouse/partner's involvement in your health care.

		Never				Very Often	
a.	How often does your spouse/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your spouse/partner talk with your doctor or other medical personnel about your risk of breast or ovarian cancer?	1	2	3	4	5	Н35ь.
c.	How often does your spouse/partner keep track of what you need to do about your risk for breast or ovarian cancer?	1	2	3	4	5	Н35с.
d.	How often does your spouse/partner change their activities to assist you in your health care?	1	2	3	4	5	H35d.

18.	Has your spouse/partner attendinformed about your risk for b (1) Y	reast or ovarian	cancer and w	up sessions to become what can be done?	Н36.
19.	How much contact has your sp for breast or ovarian cancer?	oouse/partner had	d with medic	cal personnel concerning your risk	Н37.
	Very Little or None 1 2	3 4	5 6	A lot 7	
20.	Do you feel your spouse/partn cancer and what can be done a	er is adequately: bout it?	informed cor	ncerning your risk for breast or ovarian	Н38.
	Not at All 1 2	3 4	5 6	Very Much 7	
21.	To what extent are you satisfie health care?	ed with your spo	use/partner's	•	Н39.
	Not at All 1 2	3 4	5 6	Very Much 7	
		MOOD	SECTI	ON	
1.	In the past year, have you hablue, or depressed or in which usually liked to do for fun? (1) Y	d two weeks or you lost all inter	more when i	nearly every day you felt sad, s like work or hobbies or things you	I12.
	1a. During this period, did (1) ☐ Yes		lationships s	suffer?	I12a.
	1b. During this period, did(1) ☐ Yes		ing or psych	otherapy?	I12b.
	1c. During this period, did (1) \square Yes	you get medicat (5) □ No	ion for this c	ondition?	I12c.
2.	Are you currently receiving cor emotional problems?	ounseling, psycl	notherapy, or	_	I13.
	$(1) \square \mathbf{Yes}$	(5) 🗆 No			

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the <u>Past Three Months</u>.

		Not at all	<u>A little</u>	Ouite a bit	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast or ovarian cancer. For each of the statements below, indicate the degree to which your life is affected <u>positively</u> by your risk of breast or ovarian cancer.

		Not At All	A Very Small Degree	A Small Degree	A Moderate Degree	A Great Degree	A Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
1.	Having compassion for others.	1	2	3	4	5	6	L61.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast or ovarian cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you've been doing what the item says, how much or how frequently. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Please make your answers as true FOR YOU as you can.

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4
c.	I've been saying to myself "this isn't possible."	1	2	3	4
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
e.	I've been getting emotional support from others.	1	2	3	4
f.	I've been giving up trying to deal with it.	1	2	3	4
g.	I've been taking action to try to make the situation better.	1	2	3	4
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4
m.	I've been getting comfort and understanding from someone.	1	2	3	4

		I haven't been doing this at all I	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
1.	I've been giving up the attempt to cope.	1	2	3	4
ο.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4
).	I've been expressing my negative feelings.	1	2	3	4
ŀ	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
•	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
3.	I've been thinking hard about what steps to take.	1	. 2	3	4
	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

3. The following items are to be answered only by those women who are <u>married or living with a partner</u>.

☐ Not married or living with a partner

(Skip to the last section on next page)

	I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this some 3	I've been doing this a lot 4
a. I've been denying or hiding my anger around my spouse/partner.	1	2	3	4
b. I've been denying or hiding my worries around my spouse/partner.	1	2	3	4
c. I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4
d. I've acted more positive around my spouse/partner than I feel.	1	2	3	4

15

BACKGROUND DATA SECTION

These are a few questions about your religious background that we forgot to ask on the original questionnaire.

1.	Religion	ı:	Catholic Jewish Muslim	(1)	Protestant Buddhist Other None	(4)	A3.
	1a.	How often do y (1) Less Often T		(5))	A Month or More	A3a.
	1b.	How important	are religious a	and spiritual l	peliefs in your li	fe?	A3b.
		Not at All	2	3	Ven	ry Important 5	

Once again, We thank you for all of your valued participation in this study.

 L \		





WOMEN'S HEALTH STUDY

Brother Questionnaire

Today's	Date	

ID				
110	ID			

BROTHER QUESTIONNAIRE

FAMILY HISTORY SECTION

First,	we are interested in learning about your family's experience with breast ca	ancer.			
1.	Have any of your relatives been diagnosed with breast cancer?				
	(1) \square Yes (5) \square No (3) \square I Don't Know				
2.	If Yes, how many of the following relatives been affected by (diagnosed with) breast cancer? (Record the number of relatives for each category)				

	Relative:	How Many?	
a.	Sister(s)		
b.	Mother		
c.	Grandmother(s) Maternal		
d.	Grandmother(s)Paternal		
e.	Aunt(s) Maternal		
f.	Aunt(s) Paternal		
g.	Cousin(s) Maternal		
h.	Cousin(s) Paternal		
i.	Wife		
j.	Daughter(s)		

3.	Do you think that your family is at an increased risk for breast cancer compared with other families?	B99

(1) \square Yes (5) \square No (3) \square I Don't Know

IF ANSWERED NO, GO TO QUESTION 7

Not At All Distressing				Very Distressing
1	2	3	4	5

5. Do you discuss your family's **increased risk for breast cancer** with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		Yes	N o	Not Applicable	
a.	Mother	1	5	9	B93a.
b.	Grandmother(s)	1	5	9	В93ь.
c.	Aunt(s)	1	5	9	В93с.
d.	Cousin(s)	1	5	9	B93d.
e.	Wife	1	5	9	B93e.
f.	Daughter(s)	1	5	9	B93f.
f.	Other women family members	1	5	9	B93g.

6. Compared to how often you now talk to the women in your family about their **risk for** breast cancer, how much would you prefer to talk to them about this topic?

B94.

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

7	D	1 1	. l	11	
1.	Do you wish y	you had more information	about your rami	ly's risk of breas	t cancer!

B97.

(1) **Yes**

(5) 🗆 No

(3) No Opinion

8. How often do you discuss your family's risk for breast cancer with **your sister** (who gave us your name)?

B75.

Never	Rarely	Sometimes	Often
1	2	3	4

8a. If you have these discussions, who generally initiates them?

You	Your Sister	Equally	No discussions
1	2	3	4

8b. How satisfied are you with these discussions?

B75b.

B75a.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

9. How often does **your sister** seek your support concerning the risk of breast cancer to women in your family?

B49a.

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a burden is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

GENETIC TESTING SECTION

Now, we have some questions about breast cancer diagnosis, treatment, and genetic testing.

1. We would like to know how much you have been informed about breast cancer. To what extent do you agree with the following statements?

		Strong Disagr				rongly Agree	I Don't Know	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	В20ь.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.

There is a test now available that will allow individuals to learn whether they have an altered gene (BRCA-1 or BRCA-2) which conveys an increased risk for developing breast cancer.

Were you aware that women are being offered the opportunity to take this test? 2.

B77a.

(1) **Yes**

(5) No

Were you aware that men are being offered the opportunity to take this test? 3.

B77b.

(1) \(\sum \) Yes

(5) No

Do you discuss genetic testing for breast cancer susceptibility with any of the following 4. women in your family? (Circle Not Applicable if you do not have any living relatives in that category.)

		Yes	No	Not Applicable
a.	Sister(s)	1	5	9
b.	Mother	1	5	9
c.	Grandmother(s)	1	5	9
d.	Aunt(s)	1	5	9
e.	Cousin(s)	1	5	9
f.	Wife	1	5	9
f.	Daughter(s)	1	5	9
g.	Other women family members	1	5	9

B95a.

B95b.

B95c.

B95d.

B95e.

B95f.

B95g.

B95h.

5. Compared to how often you now talk to the women in your family about genetic testing for breast cancer, how much would you prefer to talk to them about this topic?

B96.

A	Lot Less	A Little Less	Same Amount	A Little More	A Lot More
	1	2	3	4	5

Do you wish you had more information about genetic testing? 6.

B98.

- (1) **Yes**
- (5) No
- (3) No Opinion

7. How often do you discuss genetic testing for breast cancer with your sister?

B51a.

Never Rarely		Sometimes	Often	
1	2	3	4	

7a. If you have these discussions, who generally initiates them?

B52a.

You	Your Sister	Equally	No discussions
1	2	3	4

7b. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal	N o discussions
1	2	3	4	5

8.	What are your plans concerning this genetic test at the present time?
	(Please check one response).

B15c.

(1)	I	will	definitely	take	the	test	soon
-----	---	------	------------	------	-----	------	------

(2)____ I will <u>definitely</u> take the test, but I am not sure when.

(3)____ I will <u>probably</u> take the test.

(4) I am <u>undecided</u> whether I will take the test.

(5) I will probably not take the test.

(6) I will <u>definitely not</u> take the test.

9.	If you think you will probably or definitely take the test, what are your reasons for doing so?	B16a
	(Please check all that apply).	

(1)_____ To make decisions about family planning.

(2)____ To find out the risk that may be transmitted to my children.

(3) To find out about the risk to a daughter who is too young to be tested.

(4)_____ Family members want me to get testing.

(5)____ I just want to know whether I have an altered gene.

(6)____ I am worried about my own risk for cancer.

(7)_____ Other (describe) ______

10.	If you do not think you will probably or definitely take the test, what are your reasons for not doing so? (Please check all that apply).				
	(1) I am happier not knowing.				
	(2) I do not see any reason for learning if I have an altered gene.				
	(3) It would be too upsetting to learn that I have an altered gene.				
	(4) I am too worried about women in my family.				
	(5) I believe I already know whether I have an altered gene.				
	(6) There would not be much I could do if I found out I had an altered gene.				
	[7] I do not feel able emotionally to deal with testing.				
	(8) Family members do not want me to get testing.				
	(9) Risk to my insurance coverage.				
	(10) Too much hassle				
	(11) Other (describe)				
11.	How distressing is it for you to know that you may carry an altered gene which conveys an increased risk of breast cancer?	B76.			

Not At All Distressed				Very Distressed
1	2	3	4	5

Overall, how important are the opinions of the following family members in your decision whether to be tested for an altered gene associated with increased risk of breast cancer?

		Not At All	A Little	Some- what	A Great Deal	Not Applic- able	
a.	Sister(s)'s opinion matters	1	2	3	4	9	B78a.
b.	Spouse/Partner's opinion matters	1	2	3	4	9	В78ь.
c.	Mother's opinion matters	1	2	3	4	9	B78c.
d.	Daughter's opinion matters	1	2	3	4	9	B78d.
e.	Other family member(s)'s opinions matter	1	2	3	4	9	B78e.

6

13. How pressured do you feel from the following family members to get tested for an altered gene? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some- what	A Great Deal	Not Appli- cable
a.	Sister(s)	1	2	3	4	9
b.	Spouse/Partner	1	2	3	4	9
c.	Mother	1	2	3	4	9
d.	Daughter	1	2	3	4	9
e.	Other family member(s)	1	2	3	4	9

B79a.

B79b.

В79с.

B79d.

B79e.

14. How much of a **burden** is it **on you** when the women in your family pressure you to get tested for an altered gene?

B80.

No			A Great	Not applicable,	
Burden			Burden	No Pressure	
1	2	3	4	5	

15. How distressed would you be if you took the test and found that you **did not** have an altered gene which conveys increased risk of breast cancer?

B70a.

Not At All Distressed				Very Distressed
1	2	3	4	5

16. If you were to take the test and find out that you <u>did not have</u> an altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		Strong Disagr			St	Strongly Agree		
a.	I would feel wonderful.	1	2	3	4	5	B81a.	
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B81b.	
c.	I would feel relieved.	1	2	3	4	5	B81c.	
d.	I would not believe the results.	1	2	3	4	5	B81d.	
e.	I would fall apart emotionally.	1	2	3	4	5	B81e.	
f.	I would feel guilty.	1	2	3	4	5	B81f.	
g.	I would still feel anxious.	1	2	3	4	5	B81g.	

7

		Strong Disagr	ly eee		St	rongly Agree
h.	I would feel angry.	1	2	3	4	5
i.	I would feel prepared for the future.	1	2	3	4	5
j.	I would feel I had done all I needed to do.	1	2	3	4	5
k.	I would not feel very differently.	1	2	3	4	5

B81h.

B81i.

B81j.

B81k.

17. How distressed would you be if you took the test and found that you **did have** an altered gene which conveys increased risk for breast cancer?

B69a.

Not At All Distressed				Very Distressed
1	2	3	4	5

18. If you were to take the test and find out that you <u>had</u> an altered gene, what would you expect your reactions to be?

		Strong Disagr				rongly Agree	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B82a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I would not believe the results.	1	2	3	4	5	В82с.
d.	I would feel guilty.	1	2	3	4	5	B82d.
e.	I would be depressed.	1	2	3	4	5	B82e.
f.	I would feel worried about the future.	1	2	3	4	5	B82f.
g.	I would just fall apart emotionally.	1	2	3	4	5	B82g.
h.	I would feel anxious.	1	2	3	4	5	B82h.
i.	I would feel angry.	1	2	3	4	5	B82i.
j.	I would not feel very differently.	1	2	3	4	5	В82ј.

		Not A	t All	All The Time		
19.	How often do you worry about having an altered gene associated with risk for breast cancer among women?	1	2	3	4	5
20.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5
21.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5
22.	How often do you worry about developing cancer yourself?	1	2	3	4	5
23.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5

24.	How likely do you think it is that you have an altered gene which conveys increased
	risk for breast cancer in women relatives? (Please circle one)

	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
•	0	1	2	3	4	5	6	7	8	9	10

B88.

B89.

B90.

25. How much would it affect your health in the future if you had an altered gene which conveys increased risk for breast cancer in women relatives?

Not At All A Little		Somewhat	A Great Deal	I Don't Know
1	2	3	4	5

26. Overall, what do you think your risk is of developing cancer in the future?

	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Ī	0	1	2	3	4	5	6	7	8	9	10

SYMPTOMS OF STRAIN SECTION

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has One Carefully And Check The Finance Works.

Bothered You During the Past Three Months.

Not at all A little Ouite a bit Extremely

		Not at all	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	-
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	К3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	К9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

FAMILY RELATIONSHIPS SECTION

1.	Is there anyone in your life with whom you can sha holding back?	are your n	ost priv	ate feel	ings wi	thout	C21.
	(1) □ Yes (5) □ No						
1	la. Do you have that kind of relationship with your	r sister (v	vho gav	e us you	ır name	:)?	C21c.
	(1) \square Yes (5) \square No						
2.	How often do you talk to your sister? (check one	e)					C22.
	(1) Most every day (5)	Less	than one	ce a moi	nth		
	(2) A few times a week (6)	Less t	than one	ce a year	r		
	(3) A few times a month (7)	Neve	r				
	(4) Once a month						
3.	Please indicate the extent to which each of the follo	Strong Disage	gly	ntly des	Si	he trongly Agree	
3a.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
3b.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
3c.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	М3.
3d.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
3e.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
3f.	We can express feelings to each other.	1	2	3	4	5	М6.
3g.	There are lots of bad feelings in the family.	1	2	3	4	5	М7.
3h.	We feel accepted for who we are.	1	2	3	4	5	М8.
3i.	Making decisions is a problem for our family.	1	2	3	4	5	М9.
3j.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
3k.	We don't get along well together.	1	2	3	4	5	M11.
31.	We confide in each other.	1	2	3	4	5	M12.

BACKGROUND DATA SECTION

Now, we'd like to know more about you. A1. Month _____ Day ____ Year 1. Date of Birth □ 4 White \square 1 Black A2. 2. Ethnic Background: \square 2 Asian □ 5 Hispanic Other □ 6 Native American □ 3 Protestant □ 4 A3. Catholic \square 1 3. Religion: \square 2 **Buddhist** □ 5 Jewish Other □ 6 Muslim □ 3 None □ 7 How often do you attend religious services? A3a. 3a. 5 A Few Times A Month or More ☐ 1 Less Than Once a Month How important are religious and spiritual beliefs in your life? A3b. 3b. Very Important Not at All 5 2 4 1 1 Single Are you currently (please check one)? A4. 4. 2 Married 3 Not married, but living in a steady, marriage-like relationship Separated 4 5 Divorced 6 Widowed 5. If you are currently married, what was the date of your current marriage? A5. Month _____ Year _____ Is this your first marriage? (1) \square Yes (5) \square No A5a. 5a. How many children do you have? _____ A6. 6. Number of children living at home? A6a. 6b. Number who are under age 6? A6b. 6c. Number of Daughters? A6c. (3) Undecided Do you plan to have more children? (1) \square Yes (5) \square No A12. 7. 7a. If yes, how many more children? A12a.

8.	In general, would	you say your hea	lth is:			I1	L.
	☐ Excellent (1)	□ Very Good	☐ Good (3)	(4)	Fair	☐ Poor (5)	
9.	Are you currently (1) \square Yes	working for pay (outside the home?			A	7.
10.	If <u>yes</u> , about how	many hours per	week are you workir	ng for pay?		A	8.
11.	Less than 10 (1) What is the highest 1	10-20 (2)	21-30 (3)	31-40 (4)	41 or more (5)	AS	0
11.	1 ☐ Less than 9th	grade of high school gh school	5 □ 6 □ 7 □	Completed of Some graduate	ollege ate or professi		
The	following two quest	ions are option	al, but we hope the	it you will p	rovide this in	formation.	
12.	What is your househ	old's total incon	ne? (Check one)			A	10.
	(1) ☐ Less than \$ (2) ☐ \$10,000 to (3) ☐ \$20,000 to	\$19,999 (5	\$30,000 to \$3 \$40,000 to \$4 \$5) \(\subseteq \) \$50,000 to \$5	9,999 (0 to \$69,999 r than \$69,999	
13.	How many people	(adults and child	ren) does this income	e support?		A	11.

THANK YOU VERY MUCH FOR YOUR PARTICIPATION.

|--|--|--|--|--|--|





WOMEN'S HEALTH STUDY

Sister Questionnaire

Today's	Date	

m	
1D	

SISTER QUESTIONNAIRE

HEALTH SECTION

	111	ALIII S	ECTIO	<u> </u>	
1.	Have you ever been diagnosed with	Breast cancer?	(1) \square Yes	(5) No	B1u.
2.	Have you ever been diagnosed with	Ovarian cancer	? (1) \(\sum \) Yes	(5) No	B5.
	ase answer the following question ovarian cancer.				with breast
	I have never been diagnosed	with breast of	r ovarian ca	ncer. Skip to 11	
3.	When were you first diagnosed with	breast cancer?			В1.
	Month Year		t Applicable		
4.	When were you first diagnosed with	ovarian cancer	?		B5a.
	MonthYear		t Applicable		
5.	Have you received any of the follow	ing treatments?			
	Chemotherapy	(1) \(\sum \) Yes	(5) 🗆 No		B4a.
	Radiation	(1) \(\subseteq \text{Yes}	(5) No		B4b.
	Surgery	(1) Tes	(5) No		B4c.
6.	Have you ever had any of the follow	ring surgical pro	ocedures?		
	6a. Lumpectomy (Removal of	lump from brea	ıst)		B6a.
	(1) \square Yes (5) \square No	If yes, when?	Month	Year	B6a2.
	6b. Unilateral mastectomy (F	Removal of one	breast)		B6c.
	(1) \square Yes (5) \square No	If yes, when?	Month	Year	B6c2.
	6c. Bilateral mastectomy (Re		,		B6e.
	(1) \square Yes (5) \square No	If yes, when?	Month	Year	B6e2.
	6d. Hysterectomy (Removal	of uterus)			B6d.
	(1) \square Yes (5) \square No	If yes, when?	Month	Year	B6d2.
	6e. Oophorectomy (Removal o	of ovaries)			Вбь.
	(1) ☐ Yes (5) ☐ No	If yes, when?	Month	Year	B6b2.

7.	Do you currently consider you		ission? □ I Don	t Know			В3.
8.	Have you ever had a recurrence (1) \square Yes (5) \square 1		or ovarian I Don				B100.
9.	Before your diagnosis of brea to develop breast cancer, co	st cancer, ho mpared to the	w likely d he averaş	lid you thinge woman	nk you were? (Please c	ircle one)	В7.
	Much Less Likely			M	uch More Likely		
	1	2	3	4	5		
10.	Before your diagnosis of brea to develop breast cancer, co					lease circle one)	В8.
	Much Less Likely			M	uch More Likely		
	1	2	3	4	5	Skip to Question 13	
11.	How likely did you think you (Please circle one) Much Less Likely	are to deve	lop breast		mpared to th uch More Likely	e average woman?	B7a.
	1	2	3	4	5		
12.	How likely did you think you in your family? (Please o		op breast	cancer, coi	mpared to the	e women	B8a.
	Much Less Likely			M	uch More Likely		
	1	2	3	4	5		
13.	When was the last time you ha			tion does n	ot apply beca	ause of surgery.	B32.
14.	How many times have you compast six months?	nducted a bre				use of surgery.	В33.
	times	(-8)	ms questi	on does no	appry occa	use or surgery.	

15.	In general, w	vould you say your health is	:			I1.
	☐ Excellent	□ Very Good	☐ Good (3)	☐ Fair (4)	☐ Poor (5)	
16.	(Please	one year ago, how would y Check one only) Much better now than one y Somewhat better now than About the same as one year Somewhat worse now than Much worse than one year	year ago one year ago ago one year ago	h in general now?		12.
		FAMILY H	ISTORY S	ECTION		
	next set of quantities	questions, we are interes	sted in learning	about your far	mily's experie	nce with
1.	Have any of	your relatives been diagnose	ed with breast cand	cer?		B91.
	(1) 🗆 Y	Yes (5) □ No (3) □	I Don't Know			
2.	If Yes, how cancer? (Ho	many of the following relative many relatives for each ca	ives been affected tegory where appl	by (diagnosed wiicable?)	ith) breast	
		Relative:	How Many	?		
	a.	Sister(s)				B92a.
	b.	Mother				В92ь.
	c.	Grandmother(s) Maternal				B92c1.
	d.	Grandmother(s)Paternal				B92c2.
	e.	Aunt(s) Maternal				B92d1.
	f.	Aunt(s) Paternal				B92d2.
	g.	Cousin(s) Maternal				B92e1.
	h.	Cousin(s) Paternal				B92e2.
	i.	Wife				B92f.

B92g.

Daughter(s)

п	ISK IO	r breast cancer	for you to know because of their	that wo family	men in your history?	family may be	at increased	
		Not At A Distressi					Very Distressing	
		1	2		3	4	5	
	a.	Mother			1	5	9	B93a.
	a.	Mother			1	5	9	B93a.
	1	Grandmother((s)		1	5	9	В93ь.
	D.							
		Aunt(s)			1	5	9	В93с.
		Aunt(s) Cousin(s)			1	5	9	B93c. B93d.
	c.	Cousin(s)						-
	c. d. e.	Cousin(s)			1	5	9	B93d.

(3)
No Opinion

B97.

Do you wish you had more information about your family's risk for breast cancer?

7.

(1) **Yes**

(5) 🗆 No

8. How often do you discuss your family's risk for breast cancer with your sister who gave us your name?

B75.

Never	Rarely	Sometimes	Often
1	2	3	4

8a. If you have these discussions, who generally initiates them?

B75a.

You	Your Sister	Equally	No discussions
1	2	3	4

8b. How satisfied are you with these discussions?

B75b.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

9. How often does **your sister** seek your support concerning the risk of breast cancer to women in your family?

B49a.

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a burden is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

GENETIC TESTING SECTION

Now, we have some questions about breast cancer diagnosis, treatment, and genetic testing.

1. We would like to know how much you have been informed about breast cancer. To what extent do you agree with the following statements?

		Strong Disagi					I Don't Know
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9

B20a.

		Strong Disagr				rongly Agree	I Don't Know	
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.

There is a test now available that will allow individuals to learn whether they have an altered gene (BRCA-1 or BRCA-2) which conveys an increased risk for developing breast cancer.

2.	Were you aware that women are being offered the opportunity to take this test?			
	(1) \square Yes	(5) No		

3. Do you discuss genetic testing for breast cancer susceptibility with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		Yes	N o	Not Applicable	
a.	Sister(s)	1	5	9	B95a
b.	Mother	1	5	9	B95b
c.	Grandmother(s)	1	5	9	В95с
d.	Aunt(s)	1	5	9	B95d
e.	Cousin(s)	1	5	9	В95е
f.	Wife	1	5	9	B95f
f.	Daughter(s)	1	5	9	B95g
g.	Other women family members	1	5	9	B95h

4.	Compared to how often you now talk to the women in your family about genetic testing
	for breast cancer, how much would you prefer to talk to them about this topic?

В	9	6	•

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

5.	Do you wish	vou had more	information	about go	enetic testin	g?
		J				.0

B98.

(1)		Yes
\ I .	,	100

6. How often do you discuss genetic testing for breast cancer with **your** sister (who gave us your name)?

B51a.

Never	Rarely	Sometimes	Often	
1	2	3	4	

6a. If you have these discussions, who generally initiates them?

B52a.

You	You Your Sister		No discussions
1	2	3	4

6b. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

7.	What are your plans concerning this genetic test at the present time?
	(Please check one response).

B15c.

(1) I	will <u>definite</u>	ely take th	e test soon
-------	----------------------	-------------	-------------

(2) I will <u>definitely</u> take the test, but I am not sure when.

(3) I will probably take the test.

(4) I am $\underline{\text{undecided}}$ whether I will take the test.

(5) I will probably not take the test.

(6) I will definitely not take the test.

8.		think you will probably or definitely take the test, what are your reasons for doing so? se check all that apply).	B16a.
	(1)	_ To make decisions about family planning.	
	(2)	To find out the risk that may be transmitted to my children.	
	(3)	To find out about the risk to a daughter who is too young to be tested.	
	(4)	_ Family members want me to get testing.	
	(5)	_ I just want to know whether I have an altered gene.	
	(6)	_ I am worried about my own risk for cancer.	
	(7)	Other (describe)	
9.		do not think you will probably or definitely take the test, what are your reasons for ing so? (Please check all that apply).	B17a.
	(1)	_ I am happier not knowing.	
	(2)	I do not see any reason for learning if I have an altered gene.	
	(3)	_ It would be too upsetting to learn that I have an altered gene.	
	(4)	_ I am too worried about women in my family.	
	(5)	_ I believe I already know whether I have an altered gene.	
	(6)	_ There would not be much I could do if I found out I had an altered gene.	
	(7)	_ I do not feel able emotionally to deal with testing.	
	(8)	_ Family members do not want me to get testing.	
	(9)	_ Risk to my insurance coverage.	
	(10)	_ Too much hassle	
	(11)	Other (describe)	
10.	How distrant an increase	ressing is it for you to know that you may carry an altered gene which conveys sed risk of breast cancer?	В76.
		Not At All Distressed Very Distressed	

Overall, how important are the opinions of the following family members in your decision whether to be tested for an altered gene associated with increased risk for breast cancer? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some- what	A Great Deal	Not Applic- able
a.	Sister(s)'s opinion matters	1	2	3	4	9
b.	Spouse/Partner's opinion matters	1	2	3	4	9
c.	Mother's opinion matters	1	2	3	4	9
d.	Daughter's opinion matters	1	2	3	4	9
e.	Other family member(s)'s opinions matter	1	2	3	4	9

12. How pressured do you feel from the following family members to get tested for an altered gene? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some- what	A Great Deal	Not Applic- able
a.	Sister(s)	1	2	3	4	9
b.	Spouse/Partner	1	2	3	4	9
C.	Mother	1	2	3	4	9
d.	Daughter	1	2	3	4	9
e.	Other family member(s)	1	2	3	4	9

13. How much of a **burden** is it **on you** when the women in your family pressure you to get tested for an altered gene?

No	A Little	Some	A Great	Not applicable,
Burden	Burden	Burden	Burden	No Pressure
1	2	3	4	5

14. How distressed would you be if you took the test and found that you **did not** have an altered gene which conveys increased risk of breast cancer?

Not At All Distressed				Very Distressed
1	2	3	4	5

B70a.

B78a.

B78b.

B78c.

B78d.

B78e.

B79a.

B79b.

B79c.

B79d.

B79e.

B80.

15. If you were to take the test and find out that you <u>did not have</u> an altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		Strong Disagr				Strongly Agree	
a.	I would feel wonderful.	1	2	3	4	5	B81a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B81b.
c.	I would feel relieved.	1	2	3	4	5	B81c.
d.	I would not believe the results.	1	2	3	4	5	B81d.
e.	I would fall apart emotionally.	1	2	3	4	5	B81e.
f.	I would feel guilty.	1	2	3	4	5	B81f.
g.	I would still feel anxious.	1	2	3	4	5	B81g.
h.	I would feel angry.	1	2	3	4	5	B81h.
i.	I would feel prepared for the future.	1	2	3	4	5	B81i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B81j.
k.	I would not feel very differently.	1	2	3	4	5	B81k.

16. How distressed would you be if you took the test and found that you **did have** an altered gene which conveys increased risk for breast cancer?

Not At All Distressed				Very Distressed
1	2	3	4	5

B69a.

17. If you were to take the test and find out that you <u>had</u> an altered gene, what would you expect your reactions to be?

		Strong Disagr				rongly Agree	
a.	a. I would feel relieved about being more certain.		2	3	4	5	B82a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	В82ь.
c.	I would not believe the results.	1	2	3	4	5	B82c.
d.	I would feel guilty.	1	2	3	4	5	B82d.
e.	I would be depressed.	1	2	3	4	5	B82e.
f.	I would feel worried about the future.	1	2	3	4	5	B82f.
g.	I would just fall apart emotionally.	1	2	3	4	5	B82g.

		Strong Disagr		Strongly Agree		
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5
j.	I would not feel very differently.	1	2	3	4	5

B82h. B82i.

B82j.

		Not A	t All		All The Time		
18.	How often do you worry about having an altered gene associated with risk for breast cancer among women?	1	2	3	4	5	
19.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5	
20.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5	
21.	How often do you worry about developing cancer yourself?	1	2	3	4	5	
22.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5	

B83.

B84.

D 84

B85.

B86.

B87.

23. How likely do you think it is that you have an altered gene which conveys increased risk for breast cancer in women relatives? (Please circle one)

B88.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

How much would it affect your health in the future if you had an altered gene which conveys increased risk for breast cancer in women relatives?

B89.

□ Not at All

☐ A Little

☐ Somewhat

☐ A Great Deal

☐ I Don't Know (5)

Overall, what do you think your risk is of developing cancer (or developing cancer again) in the future?

B90.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

SYMPTOMS OF STRAIN SECTION

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has

Bothered You During the Past Three Months.

		Not at all	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	-
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	К3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	К9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energyslowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

FAMILY RELATIONSHIPS SECTION

1. Please indicate the extent to which each of the following items currently describes the family in which you grew up.

		you grew up.	Strong Disagr				trongly Agree	
	a.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
	b.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
	c.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	М3.
	d.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
	e.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
	f.	We can express feelings to each other.	1	2	3	4	5	M6.
	g.	There are lots of bad feelings in the family.	1	2	3	4	5	М7.
	h.	We feel accepted for who we are.	1	2	3	4	5	М8.
	i.	Making decisions is a problem for our family.	1	2	3	4	5	M9.
	j.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
	k.	We don't get along well together.	1	2	3	4	5	M11.
	l.	We confide in each other.	1	2	3	4	5	M12.
2.		Is there anyone in your life with whom you can share holding back? Yes No	e your m	ost priv	ate feel	ings wi	thout	C21.
		2a. Do you have that kind of relationship with ☐ Yes ☐ No	your sis	iter (wh	o gave	us your	name)?	C21c.
3.		How often do you talk to your sister? (check on Most every day A few times a week A few times a month Once a month Less than once a month Less than once a year Never	e)					C22.

BACKGROUND DATA SECTION

Now, we'd like to know more about you. ____ Month ____ Day ____ Year 1. Date of Birth A1. 2. White \square 1 Black \Box 4 Ethnic Background: A2. \square 2 Asian □ 5 Hispanic Native American \square 3 Other \Box 6 Religion: Catholic □ 1 Protestant □ 4 A3. 3. \square 2 Buddhist \Box 5 Jewish Muslim □ 3 Other □ 6 None □ 7 How often do you attend religious services? 3a. A3a. ☐ 5 A Few Times A Month or More ☐ 1 Less Than Once a Month 3b. How important are religious and spiritual beliefs in your life? A3b. Very Important Not at All 5 1 2 4 Are you currently (please check one)? 1 Single 4. A4. 2 Married 3 \(\superscript{\subscript{\text{Not married}}}\) but living in a steady. marriage-like relationship Separated 5 Divorced 6 Widowed If you are currently married, what was the date of your current marriage? 5. A5. Month _____ Year ____ Is this your first marriage? (1) \square Yes (5) \square No 5a. A5a. How many children do you have? _____ 6. A6. 6a. Number of children living at home? A6a. 6b. Number who are under age 6? A6b. 6c. Number of Daughters? A6c. Do you plan to have more children? (1) \square Yes (5) \square No (3) \square Undecided 7. A12. If yes, how many more children? 7a. A12a.

8.	Are you c	urrently wo	rking for pay out	side the h	nome?	•			A7.
	(1)	☐ Yes	(5) No						
9.	If <u>yes</u> , ab	out how ma	ny hours per we	ek are yo	u workin	g for pay	?		A8.
	Less than (1)	10	10-20 □ (2)	21-30 (3)		31-40	41 (or more (5)	
10.	What is the	highest leve	el of education y	ou have o	complete	d? (Check	one)		A9.
	1 ☐ Less than 9th grade 5 ☐ Completed college 2 ☐ Dropped out of high school 6 ☐ Some graduate or professiona 3 ☐ Completed high school 7 ☐ Completed graduate or profes 4 ☐ Some college						professional training		
The	following tv	vo question	is are optional,	but we	hope tha	it you will	l provide	e this information.	
11.	What is you	ır household	d's total income?	(Check	one)				A10.
	(2) 🗆 \$1	ss than \$10 0,000 to \$1 0,000 to \$2	9,999 (5)	\$40,0	000 to \$39 000 to \$49 000 to \$59	9,999	(7)	\$60,000 to \$69,99 Greater than \$69,9	
12.	How many	y people (ad	ults and children) does th	is income	e support?_		_	A11.

THANK YOU VERY MUCH FOR YOUR PARTICIPATION.

TODAY'S	DATE	
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POST-RESULTS 1: One to Two Months

Genetic Testing Section

1.	When did you	receive your results of genetic testing?	B1 01
2.	Are you the o	nly person in your family who has gotten genetic testing for breast and ovarian canon (1) \square Yes (5) \square No	er? B101a
3.	What were th	e results of testing? Negative (uninformative) for BRCA1/BRCA2 and all Family members who were tested were negative for BRCA1/BRCA2 OR you are the only person in your fam who has gotten testing (Skip to Question 4)	B1011
	2 🗆	Negative (informative) for BRCA1/BRCA2, but at least one family member was be Positive (Skip to Question 4)	found to
	3 □	Positive for BRCA1/BRCA2 (Skip to Next page, Question 5)	

When you took the test and found out that you <u>did not</u> have an altered gene associated with high risk for breast and ovarian cancer, what were your reactions? 4.

		Strong Disagr				rongly Agree	N/A	
a.	I felt wonderful.	1	2	3	4	5	-8	B18a_a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	-8	B18a_b.
c.	I felt relieved.	1	2	3	4	5	-8	B18a_c.
d.	I did not believe the results.	1	2	3	4	5	-8	B18a_d.
e.	I fell apart emotionally.	1	2	3	4	5	-8	B18a_e.
f.	I felt guilty.	1	2	3	4	5	-8	B18a_f.
g.	I still felt anxious.	1	2	3	4	5	-8	B18a_g.
h.	I felt angry.	1	2	3	4	5	-8	B18a_h.
i.	I felt prepared for the future.	1	2	3	4	5	-8	B18a_i.
j.	I felt I had done all I needed to do.	1	2	3	4	5	-8	B18a_j.
k.	I did not feel very differently.	1	2	3	4	5	-8	B18a_k.

INTERVIEWER: Skip to Page 3, Question 6

5. When you took the test and found out that you <u>had</u> an altered gene associated with high risk for breast and ovarian cancer, what were your reactions?

		Strong Disagn				rongly Agree	N/A	
a.	I felt relieved about being more certain.	1	2	3	4	5	-8	B19a_a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	-8	B19a_b.
c.	I did not believe the results.	1	2	3	4	5	-8	B19a_c.
d.	I felt guilty.	1	2	3	4	5	-8	B19a_d.
e.	I felt depressed.	1	2	3	4	5	-8	B19a_e.
f.	I felt worried about the future.	1	2	3	4	5	-8	B19a_f.
g	I fell apart emotionally.	1	2	3	4	5	-8	B19a_g.
h.	I felt anxious.	1	2	3	4	5	-8	B19a_h.
i.	I felt angry.	1	2	3	4	5	-8	B19a_i.
j.	I did not feel very differently.	1	2	3	4	5	-8	B19a_j.
k.	[For those who have daughters]. I wanted my daughters to be tested as soon as possible.	1	2	3	4	5	-8	B19a_k.

6. I am going to read a list of comments made by people after they have received their genetic test results. When you hear each comment, think about your thoughts and feelings toward the test results in terms of you. Please tell me how often each of the comments was true for you since you have received your test results, with the choices of *Not at All, Rarely, Sometimes*, and *Often*.

(INTERVIEWER NOTE: "IT" in the following questions refers to "RECEIVING TEST RESULTS")

(114)	ERVIEWER NOTE. 11 In the following q	Not at All	Rarely	Sometimes	Often	
a.	I thought about it when I didn't mean to.	0	1	3	5	B 116a.
b.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	3	5	B 116b.
c.	I tried to remove it from memory.	0	1	3	5	B116c.
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	3	5	B 116d.
e.	I had waves of strong feelings about it.	0	1	3	5	B116e.
f.	I had dreams about it.	0	1	3	5	B 116f.
g.	I stayed away from reminders of it.	0	1	3	5	B116g.
h.	I felt as if it hadn't happened or it wasn't real.	0	1	3	5	B 116h.
i.	I tried not to talk about it.	0	1	3	5	B 116i.
j.	Pictures about it popped into my mind.	0	1	3	5	B 116j.
k.	Other things kept making me think about it.	0	1	3	5	B 116k.
1.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	3	5	B 116l.
m.	I tried not to think about it.	0	1	3	5	B116m.
n.	Any reminder brought back feelings about it.	0	.1	3	5	B116n.
0.	My feelings about it were kind of numb.	0	1	3	5	B 1160.

Please answer the following two questions using a 1-5 scale, where <u>1=Not at All</u> and <u>5=All the time</u>

		Not A	t All		All Th	e Time
deve	often do you worry about loping breast cancer OR loping breast cancer again?	1	2	3	4	5
	what extent do these worries fere with your every day life?	1	2	3	4	5

Symptoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. Please listen to each one carefully and tell me the answer which best reflects how much that symptom has bothered you during the <u>PAST THREE MONTHS</u>. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and

4=1	Extr	em	elv.	
7	- 11 F FF	~111		

=Extremely.	Not at all	A little	Quite a bit	Extremely
. Suddenly scared for no reason	1	2	3	4
. Feeling fearful	1	2	3	4
Faintness, dizziness, or weakness	1	2	3	4
. Nervousness or shakiness inside	1	2	3	4
. Heart pounding or racing	1	2	3	4
. Trembling	1	2	3	4
Feeling tense or keyed up	1	2	3	4
. Headaches	1	2	3	4
Spells of terror or panic	1	2	3	4
0. Feeling restless, can't sit still	1	2	3	4
 Feeling low in energyslowed down 	1	2	3	4
2. Blaming yourself for things	1	2	3	4
3. Crying easily	1	2	3	4
4. Loss of sexual interest or pleasure	1	2	3	4
5. Poor appetite	1	2	3	4
6. Difficulty falling asleep, staying asleep	1	2	3	4
7. Feeling hopeless about the future	1	2	3	4
9. Feeling blue	1	2	3	4
19. Feeling lonely	1	2	3	4
20. Feeling trapped or caught	1	2	3	4
21. Worrying too much about things	1	2	3	4
22. Feeling no interest in things	1	2	3	4
23. Thoughts of ending your life	1	2	3	4
24. Feeling everything is an effort	11	2	3	4
25. Feelings of worthlessness	11	2	3	4

26. Are the sypmtoms we just talked about related to your receiving your genetic test results?

Yes	No
1	5

Open-ended Questions:

u feel you were given adequate information before receiving your geneue results:	B 1
Was there anything omitted that would have been helpful?	В
was mere anything offitted that would have soon see-passes	
What information was most helpful?	F
	Was there anything omitted that would have been helpful? What information was most helpful?

	or helpful thing you did to cope during this process?	
Were there any things you d	id that were not helpful? What were they?	B11
	o (M. L. Listing in order P. gives vou)	B120.
	oful during this time? (Make a listing in order R gives you) 5.	B120.
1	5	B120.
1 2	5. 6.	B120.
1	5. 6. 7.	B120.
1 2	5. 6. 7.	В120.
1	5. 6. 7.	В120.
1	5. 6. 7.	B120.

B118.

id they do for you?	
and him company did that was not helpful?	
een anything someone did that was not helpful?	
een anything someone did that was not helpful?	

6.	Are you currently Married or Living in a steady marriage-like relationship?	B122.
	(1) \square Yes (5) \square No (Skip to next page, question 9)	
If YE	S and R has not yet discussed her spouse/partner's support: What's the most helpful thing your spouse/partner has done or is doing for you?	B123.
7.	What's the most helpful thing your spouse/partner has done of its deal g	
8.	What's the most helpful thing your spouse could do for you?	B124.

Is there anything you plan to do immediately with this information?	ы

What would you tell someone who is contemplating genetic testing?	B1
Do you have any regrets about getting this testing? If yes, what are they?	B1

Are you	Are you the first person in your family to get testing?				
Will yo	ou encourage your relatives to get genetic testing or discourage them from testing?	B 129			
We ar	re trying to get a better picture of this process. What is something I didn't ask you that I d have?	В13			

TODAY'S	DATE	
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POST-RESULTS INTERVIEW--Six Month Follow-Up

INTERVIEWER: For the Introduction, Please include the following important points or read the script:

- Thank the subject again for her participation (We know we've asked a lot of her.)
- This interview is 6 months after receiving genetic test results.
- Repetition of Questions needed to compare results to our previous research and to other researchers.
- Remind subject that this interview is confidential and completely voluntary.
- Suggest that the subject may prefer to get a pen and paper to jot down the different scales that will be used.

We have asked you a lot of questions over the last several years while you were waiting for your genetic results. This interview is scheduled 6 months after you received genetic test results. We recognize that we asked many of these questions before. They are the "gold" standards in this kind of research and in order to compare our results with other researchers we need to ask them again. As you know, offering of genetic testing for breast and ovarian cancer is still relatively new and genetic counselors rely on research like this to plan services. We know that we've asked a lot of you. Thanks again for all your patience.

(1) \square Affected	(0) Unaffected
For AFFECTED Subjects Only:	

1. First of all...<u>Before</u> your own diagnosis of cancer (breast or ovarian), Did you believe that you were a member of a family at high risk for breast and ovarian cancer?

(1) \(\subseteq \text{Yes}

(5) 🗆 No

N1

Researchers are always interested in stress.

Standardized measures of stressful life events have been established with 0 representing no stress and 100 representing the greatest stress. To give you some reference points, here are some examples:

Change in residence is assigned a stress score of $\underline{20}$ Pregnancy is $\underline{40}$ Death of a close family member is $\underline{63}$ Death of a spouse is $\underline{100}$

Keepi	ing in	mind the ratings I	just mentioned:	
2.	How w	yould you rate the stress a cancer?	ss of being a member of a family at increased risk of breast and	N2
		Being a member of a	high risk family	
3.	UNA	FFECTED:	AFFECTED:	
	Нуро	thetically	Thinking about when you were first diagnosed with cancer (breast or ovarian)	
	How v	vould you rate the stre	ss of being diagnosed with cancer?	
		Diagnosis of cancer		N3
4.	Now, I	how would you rate th t which you actually re	e stress of receiving your test results? [By that, I only am referring eceived your results.]	to the
		Stress of receiving re		N4
5.	When your te	you signed up for the est results would be?	study and gave your blood sample, rate how stressful you thought r	eceiving
		Stress you had thoug	ht getting your test results WOULD be	N5
6.	it was		whole process of getting results went very smoothly, while others to the been both pleased and annoyed by the information they received be given - that sort of thing. Using our stress ratings, how would yo get results?	
		Process to get results	S	N6
	6a.	What about the process could be imp	ess has been stressful? Do you have any suggestions for how the proved?	N6a

(more space over) ___

						·	
lext, ance	we ar	e interes he past (ted in any recent ev 5 months	eents in your fa	mily related to	cancer and ri	sk for
•	To you What i	ır knowled s their rela	dge, have any of your fa ationship to you? Do yo	mily members recount and the mutation	eeived genetic test tion was found? Po	results in the passistive or Negative	t 6 montl e?
		(:	1) \square Yes (5) \square No	(Skip to Next Que	estion)		
	Total #	# Received	l Results:				N81
	10411		ship to R:	Positive Mutation Found	Negative No Mutation Found	Don't Know	
	a.			1	0	-9	N8a
	b.			1	0	-9	N8b
					0	-9	N8c
	C.	nny family (1) □ Ye	members declined reces		in the past 6 month		
		(1) Te		iving test results (N9t
		(1) Tell # I	s (5) \(\sum \) No (Skip to	iving test results (N 9t
		(1) Ye Total # I a. b.	s (5) \(\sum \) No (Skip to	iving test results (Next Question)			N 90
		(1) Tell # I	s (5) \(\sum \) No (Skip to	Next Question) N9a N9b			N91
	Have a	(1) Ye Total # I a. b. c.	s (5) \(\sum \) No (Skip to Declined Results: \(\sum \) Relationship to R:	Next Question) N9a N9b N9c	in the past 6 month	ns)?	N9t
	Have a	(1) \(\sum \) Ye Total # I a. b. c.	s (5) \square No (Skip to Declined Results: Relationship to R: members received a new street (5) \square No (Skip to Pecchined Results: No (Skip to Pecchined Results: No (Skip to Pecchined Results:	Next Question) N9a N9b N9c w diagnosis of car	in the past 6 month	ns)?	N9t
	Have a	(1) \(\sum \) Ye Total # I a. b. c.	s (5) \square No (Skip to Declined Results:	Next Question) Next Question N9a N9b N9c w diagnosis of car (Skip to Next Question)	in the past 6 month	ns)?	
	Have a	(1) \(\sum \) Ye Total # I a. b. c.	s (5) \square No (Skip to Declined Results: Relationship to R: members received a new street (5) \square No (Skip to Pecchined Results: No (Skip to Pecchined Results: No (Skip to Pecchined Results:	Next Question) N9a N9b N9c w diagnosis of car	in the past 6 month	ns)?	
	Have a	(1) \(\sum \) Ye Total # I a. b. c. any family	s (5) \square No (Skip to Declined Results: Relationship to R: members received a new street (5) \square No (Skip to Pecchined Results: No (Skip to Pecchined Results: No (Skip to Pecchined Results:	Next Question) Next Question N9a N9b N9c w diagnosis of car (Skip to Next Question)	in the past 6 month	ns)?	

10.	Have a	ny family memb (1) □ Y				Next Questi):		
	Total #	† Prophylactic St	urgerv:						_ N	111
	101417	Relationship to		P	Prop	hylactic Proc	edure:			
	a.	-							N11a	
	b.								N11b	
	c.								N11c	
11.	month	any family members)? [such as treation (1) Family Members	tment, surger (5) \Box	ry, or dea No (Ski	atn? ip to	l Next Questi		or risk of cand		112
	Total t	Relationship to				nt related to ca	ancer:			
	0	Ttomas-p						N1	2a	
	a.							N1	2b	
	b.							N1	2c	
	C.									
12.	please	a 5 point scale vertell us how often relative in a cate prequently. How	n you talk wi zory nlease a	th the for inswer th	mow ne ai	nng people in uestion thinki	ng about the		whom you ta	
			Not at All	Rarely	y	Sometimes	Often	A Lot	Not Applicable	
a.	Spous	e	1	2		3	4	5	-8	N28a
b.	Daugh		1	2		3	4	5	-8	N28b
c.	Son		1	2		3	4	5	-8	N28c
d.	Mothe	er	1	2		3	4	5	-8	N28d
e.	Grand	mother	1	2		3	4	5	-8	N28e

Sister

Aunt

Cousin

f.

g.

h.

N28f

N28g

N28h

-8

-8

-8

5

5

5

4

4

4

3

3

3

2

2

2

1

1

1

13. Using the same scale, How often do you talk with each of these same people when something important and/or difficult happens in your life?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N29a
b.	Daughter	1	2	3	4	5	-8	N29b
c.	Son	1	2	3	4	5	-8	N29c
d.	Mother	1	2	3	4	5	-8	N 29d
e.	Grandmother	1	2	3	4	5	-8	N29e
f.	Sister	1	2	3	4	5	-8	N29f
g.	Aunt	1	2	3	4	5	-8	N29g
h.	Cousin	1	2	3	4	5	-8	N29h

14. Before you actually got your results, How often did you discuss getting genetic testing for breast and ovarian cancer with these family members?

							_	
		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N30a
b.	Daughter	1	2	3	4	5	-8	N30b
c.	Son	1	2	3	4	5	-8	N30c
d.	Mother	1	2	3	4	5	8	N30d
e.	Grandmother	1	2	3	4	5	-8	N30e
f.	Sister	1	2	3	4	5	-8	N30f
g.	Aunt	1	2	3	4	5	-8	N30g
h.	Cousin	1	2	3	4	5	-8	N30h

15. In the last six months since you received your genetic test results, How often have you discussed the results with each of them?

		Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	
a.	Spouse	1	2	3	4	5	-8	N31a
b.	Daughter	1	2	3	4	5	-8	N31b
c.	Son	1	2	3	4	5	-8	N31c
d.	Mother	1	2	3	4	5	-8	N31d

e. Grandmother 1 2 3 4 5 -8 N31f f. Sister 1 2 3 4 5 -8 N31f g. Aunt 1 2 3 4 5 -8 N31g			Not at All	Rarely	Sometimes	Often	A Lot	Not Applicable	N31e
f. Sister 1 2 3 4 5 -8 N31g g. Aunt 1 2 3 4 5 -8 N31h	e.	Grandmother	1	2	3	4	3	-0	1
g. Aunt 1 2 3 4 5 -8 N31g 1 2 3 4 5 -8 N31h		Sister	1	2	3	4	5	-8	N31f
-8 N31h	1.		1	2	3	4	5	-8	N31g
	g.	Aunt	<u> </u>		-		5	-8	N31h
	h.	Cousin	1	2	3	4		L]

N32

Overall, to what extent do your family members talk about themselves as being a family at high risk for breast or ovarian cancer? 16.

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Related Comments:		

When you catch-up on what's going on in your family, to what extent are people's experiences 17. with breast or ovarian cancer a topic of conversation?

N33

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Related Comments:	

18. In your family, to what extent do you agree on how to manage risk for breast or ovarian cancer?

Not at All	Rarely	Sometimes	Often	A Lot
1	2	3	4	5

Can you give me some	examples of ways this comes up?
Came y 2 22 G2 1 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	
Have there been any di	isagreements about managing risk for cancer in your family? Can you tell me
about mat:	

For those receiving uninformative results (No BRCA1 and BRCA2 Alterations Found AND No one in their family has a BRCA1 or BRCA2 alteration even though there is a family history of breast cancer):

- 19. Even though no alteration was found for BRCA1 and BRCA2, Do you believe there is a possibility that you have another altered gene conveying an increased risk for breast and ovarian cancer?
 - (1) \(\sum \) Yes
- (5) No

N13

- 20. If it becomes available, do you intend to get testing for any additional genes related to risk of breast and ovarian cancer?
 - (1) \(\subseteq \text{Yes}
- (5) \(\subseteq \text{No} \)
- (3) Unsure

N14

Now I want to ask you about the impact receiving results had on you. I'm going to ask you to rate the effect that getting your genetic results has had on different areas in your life. Using a scale of 1-5, 1=Very Negative Effect, 2=Somewhat Negative Effect, 3=No Effect, 4=Somewhat Positive Effect, and 5=Very Positive Effect...

21. On the whole, what effect has testing had on your life?

Very	Somewhat	No Effect	Somewhat	Very
Negative	Negative		Positive	Positive
Effect	Effect		Effect	Effect
1	2	3	4	5

N15

				•	10
22.	Think about your everyday family life.	What effect would you say getting the genetic test results l	nas	ha	1?

Very	Somewhat	No Effect	Somewhat	Very
Negative	Negative		Positive	Positive
Effect	Effect		Effect	Effect
1	2	3	4	5

N16

23. What effect has getting your results had on your work in and outside of the home?

Very	Somewhat	No Effect	Somewhat	Very
Negative	Negative		Positive	Positive
Effect	Effect		Effect	Effect
1	2	3	4	5

N17

24. What effect has getting your results had on your concerns for your child's/children's future?

Very	Somewhat	No Effect	Somewhat	Very
Negative	Negative		Positive	Positive
Effect	Effect		Effect	Effect
1	2	3	4	5

N19

25. Has getting these results changed the likelihood that you will have (more) children?

No/Fewer	N o	More
Children	Change	Children
1	2	3

N22

26. How has it affected your anxiety about the <u>future</u>?

Less	N o	More
Anxiety	Change	Anxiety
1	2	3

N18

27. Are there any OTHER areas that testing has affected?

N20

(1) ☐ Yes (5) ☐ No

27a. Please List Other Areas Affected by Genetic testing:

N20a

(more	space	over)	

Now using a different scale of 1-5, 1=Not at All, 2=A Little, 3=Some, 4=Quite a Bit, and 5=Very Much...

28. How much has getting test results changed your health care decision(s)?

Not	A	Some	Quite	Very
At All	Little		a Bit	Much
1	2	3	4	5

29. In general, how much has getting genetic results changed your life?

Not	A	Some	Quite	Very
At All	Little		a Bit	Much
1	2	3	4	5

Symptoms of Strain Section

I'm going to be reading you some Symptoms Of Strain that people sometimes have. Please listen to each one carefully and tell me the answer which best reflects how much that symptom has BOTHERED you during the **PAST THREE MONTHS**. Please use the following scale: 1=Not at all, 2=A little, 3=Quite a bit, and 4=Extremely.

		Not at all	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>
1.	Suddenly scared for no reason	1	2	3	4
2.	Feeling fearful	1	2	3	4
3.	Faintness, dizziness, or weakness	1	2	3	4
4.	Nervousness or shakiness inside	1	2	3	4
5.	Heart pounding or racing	1	2	3	4
6.	Trembling	1	2	3	4
7.	Feeling tense or keyed up	1	2	3	4
8.	Headaches	1	2	3	4
9.	Spells of terror or panic	1	2	3	4
10.	Feeling restless, can't sit still	1	2	3	4

9

N21

N23

K1.

K2.

K3.

K4.

K5.

K6.

K7.

K8.

K9.

K10.

		Not at all	<u>A little</u>	Quite a bit	<u>Extremely</u>
11.	Feeling low in energyslowed down	1	2	3	4
12.	Blaming yourself for things	1	2	3	4
13.	Crying easily	1	2	3	4
14.	Loss of sexual interest or pleasure	1	2	3	4
15.	Poor appetite	1	2	3	4
16.	Difficulty falling asleep, staying asleep	1	2	3	4
17.	Feeling hopeless about the future	1	2	3	4
18.	Feeling blue	1	2	3	4
19.	Feeling lonely	1	2	3	4
20.	Feeling trapped or caught	1	2	3	4
21.	Worrying too much about things	1	2	3	4
22.	Feeling no interest in things	1	2	3	4
23.	Thoughts of ending your life	1	2	3	4
24.	Feeling everything is an effort	1	2	3	4
25.	Feelings of worthlessness	1	2	3	4

K26. To what extent are these current symptoms a result of getting genetic testing?

Not	A	Some	Quite	Very
At All	Little		a Bit	Much
1	2	3	4	5

The following questions are about any counseling or psychotherapy you have received in the past, either related to cancer issues or other personal issues.

Have you <u>ever</u> seen any kind of counselor, therapist, psychologist, psychiatrist, or any other person like that for personal or emotional problems? (ASK the following probes as necessary: What type of person did you see? Why did you go? Have you ever seen someone for cancer issues? For dealing with Genetic Testing?)

Outpatient psychiatric or psychological treatment or counseling in the past 12 months:

- Exclude Educational Sessions with a Genetic Counselor
- Include treatment in outpatient and day hospital settings

- guidance or vocational counseling = No

- Axis I-type symptoms, even if not diagnosed = 3

- bereavement counseling = 4

- didactic analysis or equivalent ONLY for training/education = 8

- Family therapy ONLY to help a family member (subject did not discuss his/her own problems) = 8 Code all reasons that apply Next Page

Post-Results.2 Interview Version 5/98

K11.

K12.

K13.

K14.

K15.

K16.

K17.

K18.

K19.

K20.

K21.

K22.

K23.

K24.

K25.

K26

CODE ALL REASONS THAT APPLY:	
a NO (Skip to Question N25)	N24a
b TES - Depression	N24b
c YES - Other Psychiatric (Axis I)	N24c
d YES - Interpersonal, Behavioral, Stress, Family, Developmental, etc.	N24d
e YES - Cancer Issues (diagnosis)	N24e
f YES - Genetic Testing Issues	N24f
g YES - Other (Specify Next page)	N24g
Specify treatment(s) and problem(s)	
Are you <u>currently</u> seeing any kind of counselor, therapist, psychologist, psychiatrist, or any oth like that for personal or emotional problems? (ASK the following probes as necessary: What ty person are you seeing? Why are you going? Are you seeing someone for cancer issues? For defenetic Testing?) Outpatient psychiatric or psychological treatment or counseling in the past 12 months: - Exclude Educational Sessions with a Genetic Counselor - Include treatment in outpatient and day hospital settings - guidance or vocational counseling = No - Axis I-type symptoms, even if not diagnosed = 3 - bereavement counseling = 4 - didactic analysis or equivalent ONLY for training/education = 8 - Family therapy ONLY to help a family member (subject did not discuss his/her own problems)	ealing with
CODE ALL REASONS THAT APPLY:	NO5 -
a NO (Skip to Question N26)	N25a N25b
b YES - Depression	N256 N25c
c YES - Other Psychiatric (Axis I)	N25d
d YES - Interpersonal, Behavioral, Stress, Family, Developmental, etc.	N25e
e YES - Cancer Issues (diagnosis)	N25e N25f
f YES - Genetic Testing Issues	N251 N25g
g	
Specify treatment(s) and problem(s)	
•	

32.	114.0	(1) Yes (Record Meds b	elow)	(5) 🗆 No	o (Skip to	Score H	opkins)			N2	26
33.	What medic Were	medication(s) did you take cation? Were the reasons the reasons for starting the	te? How for <u>starting</u> is medic	long did yong this medation relate	ou take t lication i d to you	his med related t r genetic	ication? A o your ca c testing o	Are you ncer or or receiv	still taki your risk ving gene	ing this for cance etic test re	er? :sults?
		Medications for emotio - Inlude St. John's Wa - Exclude Hormonal T	art			anxiety:					
		Medication:	Code:	Duration (Months)	Curro Tak	ently ing?	Relate Cano			ated to Testing?	
	a.				(1) □Yes	(5) □No	(1) □Yes	(5) □No	(1) □Yes	(5) □No	N27a
	b.				(1) □Yes	(5) □No	(1) □Yes	(5) □No	(1) □Yes	(5) □No	N27b
	c.				(1) □Yes	(5) □No	(1) □Yes	(5) □No	(1) □Yes	(5) □No	N27c
	d.				(1) □Yes	(5) □No	(1) □Yes	(5) □No	(1) □Yes	(5) □No	N27d
	e.				(1) □Yes	(5) □No	(1) □Yes	(5) □No	(1) □Yes	(5) □No	N27e
	f.				(1) □Yes	(5) □No	(1) □Yes	(5) □No	(1) □Yes	(5) □No	N27f
	<u></u>				!					110044010101000011100000	
INTI	ERVIE	WER: Go back to Score swers for K1-K25:	Hopkin	s-25 (Sym _l	otoms of	Strain	Section, 1	p. 8) by	adding	up the	
		If score		r more," <u>C</u> r less," <u>Ski</u>					SCID	Comple	ted
			***************************************		*****************			,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		******************************	*************
WHI	EN FII	NISHED WITH INTE	RVIEW	BE SUR	Е ТО	TELL	SUBJEC	CT:			
:	Ve hav uestio	ve a short questionnai ns.	re that	we well r	nail in	about	a week	with s	ome di	fferent	
• V	Ve'd li	ike to contact everyor	ne (one	last time) in abo	out 6 m	nonths, i	if that	is okay	.	
• (Check .	Address									
• T	hank	subject.	.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	************************			***************************************				,

Have you ever taken medication for emotional distress, depression, or anxiety?

32.

CSID	
INTERVIEW	ER

SCID Modules--Post-Results.2

6 Month Follow-Up Interview

Depression.

We will be assessing Current Major Depressive Episode using the module from the SCID, A1-A5.

(add to A2, item 3: Is that a significant weight loss for you?)

(add to A2, item 4:

Insomnia:

- more than 60 minutes falling asleep

- more than 30 minutes midnight awakening

- more than 60 minutes early morning awakening

Hypersomnia:

- very early to bed

- very late rising

- extended naps (greater than 2 hours)

We then asses Current Dysthymia, A38-A42.

Anxiety Disorders.

We assess Current Generalized Anxiety Disorder, F31-F35.

We then assess Current Mixed Anxiety Disorder, J5-J8.

D 11. 1		
Edited:		

3

3

2

A1

A2

1

1

9

SCID-I (DSM-IV)

IN THIS SECTION, MAJOR DEPRESSIVE, DYSTHYMIC DISORDER, MOOD DISORDER DUE TO A GENERAL MEDICAL CONDITION, AND SUBSTANCE-INDUCED MOOD DISORDER ARE EVALUATED.

CURRENT MAJOR DEPRESSIVE EPISODE

Now I am going to ask you some more questions about your mood.

In the last month...

...has there been a period of time when you were feeling depressed or down most of the day nearly every day? (What was that like?)

> IF YES: How long did it last? (As long as two weeks?) When did it begin?

...what about having little interest or pleasure in doing things?

> IF YES: Was it nearly every day? How long did it last? (As long as two weeks?)

MDE CRITERIA

CURRENT MDE

A. Five (or more) of the following symptoms have been present during the same two week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

- (1) depressed mood most of the day, nearly every day, as indicated either by subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children and adolescents. can be irritable mood.
- (2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account of observation made by others)

NOTE: WHEN RATING THE FOLLOWING ITEMS, CODE "1" IF CLEARLY DUE TO A GENERAL MEDICAL CONDITION, MOOD-INCONGRUENT **DELUSIONS OR** HALLUCINATIONS

FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS IN THE PAST MONTH (OR ELSE THE PAST TWO WEEKS IF EQUALLY DEPRESSED FOR THE ENTIRE MONTH

During this (TWO WEEK PERIOD)...

PERIOD)						
did you lose or gain any weight? (How much?) (Were you trying to lose weight?) IF NO: How was your appetite? (What about compared to your usual appetite?) (Did you have to force yourself to eat?) (Eat [less/more] than usual?) (Was that nearly every day?)	(3) significant weight loss when not dieting, or weight gain (e.g., a change of more than 5% of body weight in a month) or decrease or increase in appetite nearly every day. Note: in children, consider failure to make expected weight gains. Check if: weight loss or decreased appetiteweight gain or increased appetite	?	1	2	3	A3 A4 A5
how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying asleep, waking too early, OR sleeping too much? How many	(4) insomnia or hypersomnia nearly every dayCheck if:insomnia	?	1	2	3	A6
hours a night compared to usual? Was that nearly every night?)	hypersomnia					A8
were you so fidgety or restless that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)	?	1	2	3	A9
IF NO: What about the opposite talking or moving more slowly than is normal for you? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	NOTE: CONSIDER BEHAVIOR DURING THE INTERVIEW Check if:psychomotor retardationpsychomotor agitation					A10 A11
what was your energy like? (Tired all the time? Nearly every day?)	(6) fatigue or loss of energy nearly every day	?	1	2	3	A 12
? = inadequate information	1 = absent or false $2 = subthresho$	old	3 =th	reshold	or true	

SCID (DSM-IV)	Current MDE	(WHS 5/98)	Mood	Episod	es		A.3
During this time how did you feel about yourself? (Worthless?) (Nearly every day?) IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)	(7) feelings of wo excessive or inappropriately which may be delinearly every day (reself-reproach or gubeing sick) NOTE: CODE "1 ONLY LOW SELL check if:	ropriate guilt usional) not merely nilt about " OR "2" IF	?	1	2	3	A13
every any .,	worthless inappropri	ate guilt					A15
did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?)	(8) diminished absolute concentrate, or inconcentrate, or inconcen	lecisiveness, either by or as	?	1	2	3	A16
IF NO: Was it hard to make decisions about everyday things? (Nearly every day?)	check if: diminished indecisiven	ability to think ess					A17 A18
were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself? IF YES: Did you do anything	(9) recurrent thou (not just fear of dy suicidal ideation w specific plan, or a attempt or a specific committing suicide	ving), recurrent vithout a suicide Tic plan for	?	1	2	3	A19
to hurt yourself?	NOTE: CODE "1 MUTILATION W INTENT	" FOR SELF- VO SUICIDAL					
	Check if: thoughts suicidal specific suicide a	plan					A20 A21 A22 A23
	AT LEAST FIVE ABOVE SXS [A CODED "3" AND ONE OF THESE OR (2)	(1-9) ARE OAT LEAST IS ITEM (1)	*CU DYS DISC	1 0 TO RREN THYM ORDE	IIC	3	A24
	IF UNCLEAR, PAGE A.1	GU IU					

IF UNCLEAR: Has (depressive episode/OWN EQUIVALENT) made it hard for you to do your work, take care of things at home, or get along with other people?

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

? 1 2 3 A25
GO TO
*CURRENT
DYSTHYMIC
DISORDER*
A.38

Just before this began, were you physically ill?

Just before this began, were you taking any medications?

IF YES: Any change in the amount you were taking?

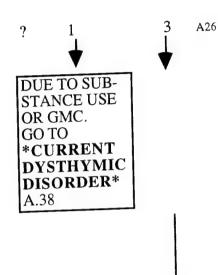
Just before this began, were you drinking or taking any street drugs?

C. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF GENERAL MEDICAL
CONDITION OR
SUBSTANCE MAY BE
ETIOLOGICALLY
ASSOCIATED WITH
DEPRESSION, GO TO
GMC/SUBSTANCE
A.43 AND RETURN HERE
TO MAKE RATING OF "1" OR
"3."

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease, Huntington's disease, cerebrovascular disease, metabolic and endocrine conditions [e.g., B-12 deficiency, hypothyroidism], autoimmune conditions [e.g., systemic lupus erythematosus], viral or other infections [e.g., hepatitis, mononucleosis, HIV], and certain cancers [e.g., carcinoma of the pancreas]

Etiological substances include alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics, and other or unknown substances (e.g., steroids)





A29

(Did this begin soon after someone close to you died?)

Current MDE

D. Not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

3 A27 1 NOT **SIMPLE** SIMPLE BEREAVE-BEREAVE-MENT MENT GO TO **CONTINUE** *CURRENT DYSTHYMIC BELOW **DISORDER*** A.38

MAJOR DEPRESSIVE **EPISODE** CRITERIA A, B, C and D are coded "3"

3 A28 1 GO TO **CURRENT** *CURRENT **DYSTHYMIC MAJOR DEPRESSIVE DISORDER* EPISODE** A.38

How many separate times have you been (depressed/OWN EOUIVALENT) nearly every day for at least two weeks and had several of the symptoms that you described, like (SXS OF WORST EPISODE)?

How old were you when (CURRENT MAJOR **DEPRESSIVE EPISODE**) started?

Total number of Major Depressive Episodes, including current (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)

Age at onset of Current Major Depressive Episode

Mo/Yr: ____/ ___ Age:____

IF UNCLEAR, ESTABLISH WHETHER MDE OR CANCER DX. CAME FIRST. CODE THIS INFORMATION ON SUMMARY SCORE SHEET.

DYSTHYMIC DISORDER (CURRENT ONLY)

-> IF NO MAJOR DEPRESSIVE EPISODE IN THE PAST TWO YEARS: For the past couple of years, have you been bothered by depressed mood most of the day, more days than not? (More than half the time?)

IF YES: What was that like?

- -> IF CURRENT MAJOR DEPRESSIVE EPISODE: Let's review when you first had most of the symptoms of (CURRENT MAJOR DEPRESSIVE EPISODE). For the two years prior to (BEGINNING DATE), were you bothered by depressed moods, most of the day, more days than not? (More than half the time?)
- -> FOR A PAST MAJOR DEPRESSIVE EPISODE DURING THE PAST TWO YEARS: Let's review when you first had most of the symptoms of FIRST MET CRITERIA FOR (PAST MAJOR DEPRESSIVE EPISODE) and the point at which you no longer had most of the symptoms. Since the (DATE OF NO LONGER MEETING CRITERIA), have you still been bothered by depressed mood, so that you have been depressed for most of the day, more days than not?

IF YES: For the two years prior to (DATE OF **BEGINNING OF PAST** MAJOR DEPRESSIVE EPISODE), were you bothered by depressed mood, most of the day, more days than not? (More than half the time?)

DYSTHYMIC DISORDER CRITERIA

A. Depressed mood (or can be irritable mood in children and adolescents) for most of the day, for more days than not, as indicated either by subjective account or observation made by others, for at least two years (one year for children and adolescents)

?	1 	2	3	A163
G A	GO TO CURRE ENERA NXIET ISORD F.31	LIZEI Y	D	

FIRST MET CRITERIA FOR **CURRENT MAJOR** DEPRESSIVE EPISODE (see A.5):

Mo/Yr: ____/ ___ Age: ____

PAST MAJOR DEPRESSIVE EPISODE (see A.17):

Mo/Yr: ____/ ___ Age: ____

NO LONGER MET CRITERIA FOR PAST MAJOR DEPRESSIVE EPISODE IN PAST TWO YEARS: Mo/Yr: ____/ ___ Age: ____

•								
SCID-I (DSM-IV)	Dysthy	mic Disorder	(WHS 5/98)	Moo	d Episo	odes		A .39
During these periods of (OW EQUIVALENT FOR CHRO DEPRESSION), do you often	NIC	B. Presence, w two (or more) o	hile depressed, of f the following:					
lose you appetite?(What abovereating?)	oout	(1) poor appeti	te or overeating	?	1	2	3	A164
have trouble sleeping or sle	eep	(2) insomnia or	hypersomnia	?	1	2	3	A165
have little energy to do thin feel tired a lot?	ngs or	(3) low energy	or fatigue	?	1	2	3	A166
feel down on yourself? (F worthless, or a failure?)	eel	(4) low self-este	eem	?	1	2	3	A167
have trouble concentrating making decisions?	g or	(5) poor concer making decision	ntration or difficulty	?	1	2	3	A168
feel hopeless?		(6) feelings of	hopelessness	?	1	2	3	A169
		AT LEAST TW SYMPTOMS C	7O "B" CODED "3"	*C'GE	GO TO URRE NERA XIET SORDI F.31	LIZED Y	3	A170
What is the longest period of during this period of long-last depression, that you felt ok? DYSTHYMIC SYMPTOMS	sting (NO	person has never symptoms in A than two month NOTE: CODE	hildren or the disturbance, the er been without the and B for more as at a time. "1" IF NORMAL T LEAST TWO	*C GE AN	GO TO URRE ENERA EXIET SORD F.31	NT LIZED Y	3	A171

?

1

GO TO

ANXIETY

*CURRENT

DISORDER*

F.31

GENERALIZED

2

A172

A173

3

How long have you been feeling this way? (When did this begin?)

COMPARE ONSET OF DYSTHYMIC SXS WITH DATES OF PAST MAJOR DEPRESSIVE EPISODES TO DETERMINE IF THERE WERE ANY MAJOR DEPRESSIVE EPISODES IN FIRST TWO YEARS OF DYSTHYMIC DISORDER.

IF MAJOR DEPRESSIVE EPISODE PRECEDED DYSTHYMIC SXS: Now I want to know whether you got completely back to your usual self after that (MAJOR DEPRESSIVE EPISODE) you had (DATE), before this long period of being mildly depressed? (Were you back to your usual self for at least two months?)

D. No major depressive episode during the first two years of disturbance (one year for children and adolescents); i.e., not better accounted for by chronic Major Depressive Disorder in partial remission.

Age at onset of current Dysthymic Disorder (CODE 99 IF UNKNOWN)

Note: There may have been a previous Major Depressive Episode provided there was a full remission (no significant signs or symptoms for two months) before development of the Dysthymic Disorder. In addition, there may be superimposed episodes of Major Depressive Disorder, in which case both diagnoses may be given.

NOTE: CODE "3" IF NO PAST MAJOR DEPRESSIVE EPISODES OR IF MAJOR DEPRESSIVE EPISODES WERE NOT PRESENT DURING THE FIRST TWO YEARS OR IF THERE WAS AT LEAST A TWO MONTHS PERIOD WITHOUT SYMPTOMS PRECEDING THE ONSET.

E. Has never had a Manic Episode or an unequivocal Hypomanic Episode.

1 GO TO *CURRENT GENERALIZED ANXIETY DISORDER* F.31

3

3

NOT

CON-

TINUE

SUPER-

IMPOSED

A174

A175

F. Does not occur exclusively during the course of a chronic psychotic disorder, such as Schizophrenia or Delusional Disorder.

NOTE: CODE "3" IF NO CHRONIC PSYCHOTIC DISORDER OR IF NOT SUPERIMPOSED ON A CHRONIC PSYCHOTIC DISORDER.

1 = absent or false

2 = subthreshold

3 =threshold or true

DISORDER* F. 31

GO TO

*CURRENT

ANXIETY

GENERALIZED

? = inadequate information

A176

3

Just before this began, were you physically ill?

> IF YES: What did the doctor say?

Just before this began, were you taking any medications?

> IF YES: Any change in the amount you were taking? Did you begin a new medication?

Just before this began, were you drinking or using any street drugs?

IF UNCLEAR: How much do your depressed feelings interfere with your life?

G. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF GENERAL MEDICAL COND-ITION OR SUBSTANCE MAY BE ETIOLOGICALLY ASSOC-IATED WITH DEPRESSION, GO TO *SUBSTANCE/ GMC* A.43 RETURN HERE AND MAKE RATING OF "1" OR "3"

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease, Huntington's disease, cerebrovascular disease, metabolic and endocrine conditions (e.g., B-12 deficiency, hypothyroidism), autoimmune conditions (e.g., systemic lupus erythematosus), viral or other infections (e.g., hepatitis, mononucleosis, HIV), and certain cancers (e.g. carcinoma of the pancreas)

Etiological substances include: alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics, and other known or unknown substances (e.g., steroids).

H. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

DYSTHYMIC DISORDER CRITERIA A, B, C, D, E, F, AND H ARE CODED "3"

IF DYSTHYMIC DISORDER Indicate specifier:

- 1- Early Onset: onset before age 21
- 2- Late Onset: onset age 21 or older

? 1 DUE TO **SUBSTANCE** USE OR GMC GO TO *CURRENT GENERALIZED ANXIETY **DISORDER*** F. 31

> PRIMARY MOOD DISORDER CONTINUE

1 GO TO *CURRENT GENER-ALIZED ANXIETY **DISORDER***, F.31

1 3 A178 **DYSTHYMIC** DISORDER

Specifier:

A179

A177

GO TO *CURRENT GENERALIZED ANXIETY **DISORDER***, F.31

1

1

GO TO

A.45

*SUB-

STANCE

INDUCED*

?

?

A188

A189

GMC/SUBSTANCE CAUSING MOOD/ANXIETY SYMPTOMS

MOOD/ANXIETY DISORDER DUE TO A GENERAL MEDICAL CONDITION MOOD/ANXIETY DISORDER DUE TO A GENERAL MEDICAL CRITERIA

IF SYMPTOMS NOT TEMPORALLY ASSOCIATED WITH A GENERAL MEDICAL CONDITION, CHECK HERE ____ AND GO TO *GENERALIZED ANXIETY DISORDER*, F.31 A187

CODE BASED ON INFORMATION ALREADY OBTAINED.

A. Prominent and persistent disturbance in mood/anxiety characterized by the following:

(1) depressed mood or markedly diminished interest or pleasure in all, or almost all, activities [FOR MOOD]

(2) prominent anxiety, panic attacks, obsession or compulsions [FOR ANXIETY]

? 1 2 3 A190

2

3

3

Do you think your (MOOD/ ANXIETY SXS) were in any way related to your (COMORBID GENERAL MEDICAL CONDITION)?

IF YES: Tell me how.

(Did the [MOOD/ANXIETY SXS] start or get much worse only after [COMORBID GENERAL MEDICAL CONDITION] began?)

IF YES AND GMC HAS RESOLVED: Did the (MOOD/ANXIETY SXS) get better once the (COMORBID GENERAL MEDICAL CONDITION) got better? B./C. There is evidence from the history, physical examination, or laboratory findings that the disturbance is the direct physiological consequence of a general medical condition and the disturbance is not better accounted for by another mental disorder (e.g., Adjustment Disorder With Depressed Mood, in response to the stress of having a general medical condition).

THE FOLLOWING FACTORS SHOULD BE CONSIDERED AND SUPPORT THE CONCLUSION THAT THE GMC IS ETIOLOGIC TO THE MOOD/ANXIETY SXS:

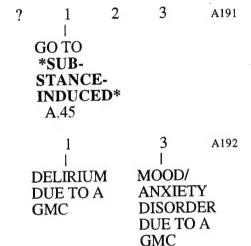
- 1) THERE IS EVIDENCE FROM THE LITERATURE OF A WELL-ESTABLISHED ASSOCIATION BETWEEN THE GMC AND MOOD/ANXIETY SYMPTOMS.
- 2) THERE IS A CLOSE TEMPORAL RELATIONSHIP BETWEEN THE COURSE OF THE MOOD/ANXIETY SXS AND THE COURSE OF THE GENERAL MEDICAL CONDI-TION.

Due to a GMC

- 3) THE MOOD/ANXIETY SYMP-TOMS ARE CHARACTERIZED BY UNUSUAL PRESENTING FEATURES (E.G., LATE AGE AT ONSET)
- 4) THE ABSENCE OF **ALTERNATIVE** EXPLANATIONS (E.G., MOOD/ANXIETY SYMPTOMS AS A PSYCHOLOGICAL REACTION TO THE GMC)

IF UNCLEAR: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

- E. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning
- D. The disturbance does not occur exclusively during the course of Delirium.



SCID-I (DSM-IV)	Substance-Induced	(WHS 5/98)	N	Mood E	pisodes		A.45		
*SUBSTANCE -INDUCI	ED SUBSTANC	SUBSTANCE-INDUCED		EPISODE BEING EVALUATED:					
MOOD/ANXIETY DISORDER*	MOOD/ANX DISORDER	CRITERIA		ent MDI nymia	E		A.1 A.38		
IF SYMPTOMS NOT TEMPO LY ASSOCIATED WITH SU STANCE, CHECK HERE _ AND RETURN TO EPISODI ING EVALUATED.	JB- 								
CODE BASED ON INFORMATION ALREADY OBTAINED.	disturbance in	nt and persistent mood/anxiety by the following:							
	diminished in	mood or markedly terest or pleasure in all, activities [FOR	?	1	2	3	A194		
	(2) prominen attacks, obses [FOR ANXIE	t anxiety, panic sion or compulsions TY]	?	1	2	3	A195		
IF NOT KNOWN: When did (MOOD/ANXIETY SYMPTO BEGIN? (Were you already (SUBSTANCE) or had you ju stopped or cut your use?	DMS) history, physical laboratory find (1) the symptom during or with substance Into withdrawal, o	vidence from the cal examination, or dings that either oms in A developed nin a month of exication or r (2) medication use y related to the	IND TO E	UCED	Z TANCE RETUR DE BEIN ED	N	A196		
Do you think your (MOOD/ANXIETY SXS) are in any verelated to your (SUBSTANCEUSE)? IF YES: Tell me how ASK ANY OF THE FOLLOWING QUESTIONS NEEDED TO RULE OUT A	accounted for Disorder that induced. Evic symptoms are by a Mood Disubstance-ind	bance is not better by a Mood/Anxiety is not substance- dence that the better accounted for isorder that is not uced might include:	IND TO I	UCED	2 TANCE RETUR DE BEIN ED	N	A197		

NEEDED TO RULE OUT A NON-SUBSTANCE-INDUCED ETIOLOGY:

IF UNKNOWN: Which came first, the (SUBSTANCE USE) or the (MOOD/ANXIETY SYMPTOMS)?

IF UNKNOWN: Have you had a period of time when you stopped using (SUBSTANCE)?

- 1) the mood/anxiety symptoms precede the onset of the Substance Abuse or Dependence
- 2) the mood/anxiety symptoms persist for a substantial period of time (e.g., about a month after the cessation of acute withdrawal or severe intoxication)

IF YES: After you stopped using (SUBSTANCE) did the (MOOD/ANXIETY SYMPTOMS) get better?

Substance-Induced

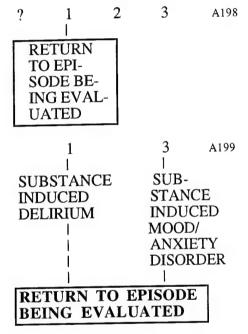
IF UNKNOWN: How much of (SUBSTANCE) were you taking when you began to have (MOOD/ ANXIETY SYMPTOMS)?

IF UNKNOWN: Have you had any other episodes of (MOOD/ ANXIETY SYMPTOMS)?

> IF YES: How many? Were you taking (SUBSTANCES) at those times?

IF UNKNOWN: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

- 3) the mood symptoms are substantially in excess of what would be expected given the character, duration, or amount of the substance used
- 4) There is evidence suggesting the existence of an independent non-substance-induced Mood/Anxiety Disorder (e.g., a history of recurrent non-substancerelated Major Depressive Episodes).
- E. The symptoms cause clinically significant distress or impairment in social, occupational, or their important areas of functioning.
- D. The disturbance does not occur exclusively during the course of Delirium.



SCID-I (DSM-IV)	GAD	(WHS 5/98)	Anxiety Disorder	'S		F.31
GENERALIZED ANXID DISORDER (CURRENT ONLY)	ETY	GENERALIZED ANXIETY DISORDER CRITERIA				
In the past six months, was the period when you were particular nervous or anxious?	nere a ılarly					
Do you also worry a lot abouthings that might happen?	t bad	A. Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at	? 1 GO TO	2	3	F135
IF YES: What do you worry about?(How no you worry about [EVENTS OR ACTIVITIES])	u nuch	least six months, about a number of events or activities (such as work or school performance)	*MIXED ANXIETY DISOR- DER,* J.5			
During the last six month would you say that you h been worrying (more day not?)	ave					
When you're worrying this v do you find that you can't sto yourself?	vay, op	B. The person finds it difficult to control the worry	? 1 GO TO *MIXED ANXIETY DISOR- DER,* J.5	2	3	F136
When did this anxiety start? COMPARE ANSWER WITH ONSET OF MOOD OR PSYCHOTIC DISORDER.	Н	F(2). Does not occur exclusively during the course of a Mood Disorder, Psychotic Disorder, or a Pervasive Developmental Disorder	? 1 GOTO *MIXED ANXIETY DISOR- DER,* J.5	2	3	F137

Anxiety Disorders

Now I am going to ask you some questions about other symptoms that often go along with being nervous.	C. The anxiety and worry are associated with at least three of the following such symptoms (with at least some symptoms present for more days than not for the past six months):					
Thinking about those periods in the past six months when you're feeling nervous or anxious						
do you often feel physically restless can't sit still?	(1) restlessness or feeling keyed up or on edge	?	1	2	3	F138
do you often feel keyed up or on edge?	•					
do you often tire easily?	(2) being easily fatigued	?	1	2	3	F139
do you have trouble concentrating or does your mind go blank?	(3) difficulty concentrating or mind going blank	?	1	2	3	F140
are you often irritable?	(4) irritability	?	1	2	3	F141
are your muscles often tense?	(5) muscle tension	?	1	2	3	F142
do you often have trouble falling or staying asleep?	(6) sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)	?	1	2	3	F143
	AT LEAST THREE "C" SXS ARE CODED "3"	*MIX	IETY ORDEF	\ *	3	F144

F145

3

CODE BASED ON PREVIOUS INFORMATION.

GAD

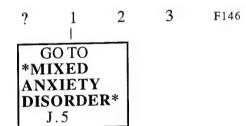
D. The focus of the anxiety and worry is not confined to the features of another Axis I Disorder, e.g. being embarrassed in public (as in Social Phobia), being contaminated (as in Obsessive-Compulsive Disorder), being away from home or close relatives (as in Separation Anxiety Disorder), gaining weight (as in Anorexia Nervosa), or having a serious illness (as in Hypochondriasis), and is not part of Posttraumatic Stress Disorder.



Anxiety Disorders

IF UNCLEAR: What effect has the anxiety, worry, or (PHYSICAL SYMPTOMS) had on your life? (Has it made it hard for you to do your work or be with your friends?)

E. The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning



F147

3

Just before you began having this anciety, were you taking any drugs, stimulants or medicines?

(How much coffee, tea, or cola do you drink a day?)

Just before these problems began, were you physically ill?

> IF YES: What did the doctor say?

F. Not due to the direct psychological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF A GENERAL MEDICAL CONDITION OR SUBSTANCE MAY BE ETIOLOGICALLY ASSOCIATED WITH THE ANXIETY, GO TO *SUBSTANCE /GMC*, A.43 RETURN HERE TO MAKÉ RATING OF "1" OR "3".

hypo-thyroidism, hypoglycemia, hyperparathyroidism, pheochromocytoma, congestive heart failure, arrhythmias, obstructive pulmonary disease, B-12 deficiency, porphyria, CNS neoplasms, vestibular dysfunction, encephalitis.

Etiological substances include: intoxicants with central nervous stimulants (e.g., cocaine, amphetamines, caffeine) or cannabis, hallucinogens, PCP, or alcohol, or withdrawal from central nervous system depressants (e.g., alcohol, sedatives, hypnotics) or cocaine

GENERALIZED ANXIETY CRITERIA A,B,C,D,E,AND F ARE CODED "3"



3 F148 GENER-ALIZED **ANXIETY** DISORDER

Etiological general medical conditions include: hyper- and pulmonary embolism, chronic

Anxiety Disorders

1

1

DUE TO SUB-

STANCE USE OR A GMC

GO TO

*MIXED

DISOR-

ANXIETY

DER,* J.5

CONTINUE

PRIMARY

ANXIETY

DISORDER

SCID-I (DSM-IV) GAD (WHS 5/98) Anxiety Disorders

CHRONOLOGY OF GENERALIZED ANXIETY DISORDER

INDICATE CURRENT SEVERITY:

- 1-- **Mild:** Few, if any, symptoms in excess of those required to make the diagnosis are present, and symptoms result in no more than minor impairments in social or occupational functioning.
- 2-- Moderate: Symptoms or functional impairment between "mild" and "severe" are present.
- 3-- Severe: Many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in social or occupational functioning.

AGE AT ONSET

IF UNKNOWN: How old were you when you first started having (SXS OF GAD)?

Age at onset of Generalized Anxiety Disorder (CODE 99 IF UNKNOWN)

GO TO *MIXED ANXIETY DISORDER* J.5.

F.35

F149

J20

J26

127

3

3

2

2

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1

During the past month, have you been

MAD

MIXED ANXIETY DISORDER CRITERIA (APPENDIX CATEGORY)

CRITERIA HAVE EVER BEEN MET FOR MAJOR DEPRESSIVE IF: DISORDER, DYSTHYMIC DISORDER, PANIC DISORDER, OR GENERALIZED ANXIETY DISORDER, CHECK HERE____ AND END SCID INTERVIEW.

MAD

CRITERIA ARE CURRENTLY MET FOR ANY OTHER ANXIETY IF: OR MOOD DISORDER (INCLUDING AN ANXIETY DISORDER OR MOOD DISORDER IN PARTIAL REMISSION), CHECK HERE____ AND END SCID INTERVIEW.

dysphoric mood lasting at least feeling bad...that is depressed or anxious one month. for most of the time? DONE B. The dysphoric mood is During those times when you're feeling accompanied by at least 1 month bad... of four (or more) of the following symptoms: NOTE: FOR EACH OF THE FOLLOWING, MAKE SURE THE SYMPTOM LASTED AT LEAST 1 MONTH 121 3 2 ? 1 (1) difficulty concentrating or ...have you had trouble concentrating or mind going blank does your mind go blank? J22 3 ? 1 2 (2) sleep disturbance (difficulty ...have you had trouble sleeping? falling or staying asleep, or restless unsatisfying sleep) J23 3 ? 1 2 ...have you felt like you were tired all the (3) fatigue or low energy time or that your energy was low? J24 3 2 ? 1 (4) irritability ...have you felt irritable or cranky? J25 1 2 3 ...did you worry a lot about things? (5) worry

(6) easily moved to tears

(7) hypervigilance

A. Persistent or recurrent

things?

...did you find yourself crying over little

...have you been watchful or on guard even when there is no reason to be?

SCID-I (DSM-IV)	MAD	(WHS 5/98)				ĺ	J .6
when looking ahead, were you expecting the worst?		(8) anticipating the worst	?	1	2	3	J28
did you feel hopeless about the fut	ıre?	(9) hopeless (pervasive pessimism about the future)	?	1	2	3	J29
did you feel down on yourself or the you were worthless?	nat	(10) low self-esteem or feelings of worthlessness	?	1	2	3	J30
		AT LEAST FOUR "B" SYMPTOMS CODED "3"	?	1 I DONE		3	J31
IF UNCLEAR: How much did these feelings interfere with your life?	bad	C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.	?	1 DONE	2	3	J32

J33

3

SCID-I (DSM-IV)

Just before you began having these symptoms, were you taking any drugs, stimulants or medicines?

MAD

(How much coffee, tea, or cola do you drink a day?)

Just before these problems began, were you physically ill? (What did the doctor say?)

D. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

1 1 **DUE TO SUBSTANCE** USE OR A GMC. *DONE*

IF A GENERAL MEDICAL CONDITION OR SUBSTANCE MAY BE ETIOLOGICALLY ASSOCIATED WITH THE ANXIETY, GO TO *GMC/SUBSTANCE*, A.43 AND RETURN HERE TO MAKE RATING OF "1" OR "3."

PRIMARY ANXIETY **DISORDER**

Etiological general medical conditions include: hyper- and hypo-thyroidism, hypoglycemia, hyper-parathyroidism, pheochromocytoma, congestive heart failure, arrythmias, pulmonary disease, pneumonia, hyperventilation, B-12 deficiency, porphyria, CNS neoplasms, vestibular dysfunction, encephalitis.

Etiological substance include: intoxication with central nervous stimulants (e.g., cocaine, amphetamines, caffeine) or cannabis, hallucinogens, PCP, or alcohol, or withdrawal from central nervous system depressants (e.g., alcohol, sedatives, hypnotics) or from cocaine.

CONTI-NUE

3

J34

E. All of the following:

(1) Has never met criteria for Major Depressive Disorder, Dysthymic disorder, Panic Disorder, or Generalized Anxiety Disorder.

(2) Does not currently meet criteria for any other Anxiety or Mood Disorder (including an Anxiety or Mood Disorder in partial remission)

(3) Not better accounted for by any other mental disorder

1 *DONE*

(WHS 5/98)

J.8

J36

CRITERIA A, B, C, D, AND E ARE CODED "3"

MIXED ANXIETY DEPRES-SIVE DIS-ORDER

AGE AT ONSET

IF UNKNOWN: How old were you when you first started having (SXS OF MAD)?

Age at onset of Mixed Anxiety Depressive Disorder (CODE 99 IF UNKNOWN)

> DONE WITH SCID

1